An exploratory study using co-design to improve palliative and end of life care for people with severe mental illness

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An exploratory study using co-design to improve palliative and end of life care for people with severe mental illness

By

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Ethical Approval

Certificate of Ethical Approval

Applicant:

Jed Jerwood

Project Title:

Improving End of Life Care for Adults with Severe Mental Illness: Understanding the views of patients, their informal care networks, and use of co-design to improve approaches to clinical practice

This is to certify that the above named applicant has completed the Coventry University Ethical Approval process and their project has been confirmed and approved as High Risk

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Abstract

Background

People with severe mental illness (SMI) have a life expectancy of up to twenty years less than the general population which is one of the biggest health inequalities in the UK. People with SMI and terminal illnesses also face multiple barriers, including stigma and prejudice from clinical staff, when accessing palliative and end of life (PEOLC) services. Little is known about the PEOLC needs and expectations of people with SMI and terminal conditions. There has been very limited research conducted which aims to develop improvements to the quality and accessibility of PEOLC for people with SMI.

Aims

The aims of this research were; to seek views of patients, and their carers, with severe mental illnesses and terminal conditions on their expectations of care; to co-design the concept and content of a clinical resource to improve care and to contribute to the development of co-design research methodologies.

Methods

The co-design process involved two stages of data collection. Initially, eight interviews were carried out, five patients and three carers were interviewed. Interview transcripts were thematically analysed and key themes developed which informed the second stage of the co-design process. Subsequently, three cohorts of participants (32 participants) took part in a series of workshops, using visual and creative methods, including stakeholders from a range of backgrounds; patients, carers, mental health and palliative and end of life care clinical staff. An iterative data analysis process was carried out throughout the rounds of data collection and the content, format and concept for a clinical resource was developed by the co-design participants and researchers.

Findings

The interview stage led to the development of four overarching themes: Stigma and Prejudice - ‘See Me, Not My Diagnosis’ Hesitancy and Avoidance – ‘Treading on Eggshells’, Collaborators in Care – ‘The Ignored Experts’ and Connections – ‘Leaning In, Not Stepping Back’.

The workshop findings identified the content and key features of a clinical resource to improve care. Key features included accessibility, interactivity, the use of patient and carer stories, the use of visual methods and the need to challenge attitudes not just provide information. Co-design methods provided a valuable approach to developing the concept and content of a clinical resource which uses visual and creative methods to improve clinician confidence. The creative and visual methods used in the workshops allowed the development of an innovative solution grounded in end user need.

Conclusions

This study offers novel understanding of the views and expectations of patients with SMI and terminal conditions, and those who care for them, on their palliative and end of life care needs. It presents the concept and content for an innovative clinical resource which aims to improve care by building confidence and knowledge in clinical staff from all healthcare settings, particularly PEOLC and mental health. The findings and recommendations are useful for clinicians, patients, carers, commissioners and policy makers.

Chapter 1 Introduction

This chapter introduces the topic and aims of the thesis, provides some background to the research topic and introduces the researcher's clinical background. The chapter goes on to outline key definitions used in the research study and describes the structure of the thesis.

1.1 Aims of Thesis

This thesis sought to explore how palliative and end of life care (PEOLC) can be improved for people living with severe mental illnesses (SMI) and terminal conditions. This was achieved by exploring patient and carer experiences and using this understanding to inform a process of co-design with clinicians, patients and carers, in order to develop a resource to improve clinical care. Previous research in this area has been minimal and limited to *describing barriers* to providing end of life care to this patient group, rather than seeking to *develop improvements* to care (Bloomer and O'Brien 2013; Duckart et al. 2010; Feely et al. 2013; Foti et al. 2005; Mental Health Foundation 2008; Shalev et al. 2017).

This study has its origins rooted in clinical practice. Observations of the large numbers of people in the mental health system with physical ill health conditions, many which were long term and likely to be incurable, led to a curiosity about the care these patients received regarding their physical health within mental health services, and their experiences of accessing other parts of the healthcare system. Similarly, within the hospice setting, the researcher observed that very few patients with histories of SMI[1] appeared to access hospice services. The researcher became curious about the quality of PEOLC experienced by this patient group. On the few occasions a patient with SMI was referred to hospice services, they appeared to raise anxieties amongst clinical staff and a lack of confidence in working with patients with SMI was highlighted. A few patients had been referred to the researcher, in his clinical role as an art psychotherapist, as an alternative way to engage with hospice services. Through accessing art psychotherapy, these patients built a relationship with the hospice and became more open to accessing other services, such as respite care and day hospice.

[1] Severe mental illness refers to conditions such as psychosis, schizophrenia and bi-polar disorder. SMI has been used as an umbrella term for people accessing secondary mental health services with diagnosed mental illnesses. See section 1.3 for a full definition of what is meant by SMI

These clinical observations led the researcher to seek to understand the issues surrounding the end of life care experiences of people with SMI, who develop terminal conditions and how care could be improved. The aims of this study were to:

- Gain an understanding of the views and experiences of patients with severe mental illness, and informal care network members, on their palliative and end of life care needs and their experiences of receiving care.
- Apply this understanding to the development of a co-designed educational/information resource to improve approaches to clinical practice.
- To contribute to the development of co-design methodologies and the analysis of co-design data.

These aims sought to improve the accessibility and quality of palliative and end of life care for people with SMI, through improving the confidence and competence of clinical staff. It aimed to use co-design methods to develop concept and content of a clinical resource to improve care. This built upon a previous underpinning literature review and a study exploring clinicians views of barriers to providing palliative and end of life care to this patient group, carried out by the researcher.

The study adopted a process of creative co-design, data collection and analysis methods to achieve these aims. The importance of developing the resource with its end users, in this case clinical staff, and the people it concerns, patients and carers, was paramount. The research sits within the participatory research paradigm in which collaboration with stakeholders is a core principal (Bergold and Thomas 2012, Boyd et al. 2012, Heron and Reason 1997, Sanders and Stappers 2014). The professional identity of the researcher, as an art psychotherapist, informed the topic of the research and also the research design and methods.

1.2 Background to Thesis

This thesis sat against a backdrop of an increased national focus on improving access to, and quality of, PEOLC in the UK since the publication of the End of Life Care Strategy in 2008 (Department of Health 2008). Community initiatives such as Dying Matters week (www.dyingmatters.org), BRUM YODO ('You Only Die Once' - a Birmingham-based collective which runs events to promote conversations about death and dying https://brumyodo.org.uk) and policy initiatives, developed by the National Council for Palliative Care (NCPC 2015), Hospice UK (Hospice UK 2013), NHS England (2015) and the National Palliative and End of Life Care Partnership (National Palliative and End of

Life Care Partnership 2015) have raised the importance and profile of PEOLC consistently at a community, strategic and policy level. The specific needs of some marginalised groups, such as black, Asian and minority ethnic (BAME) people and people with learning disabilities, have been included in these initiatives. However, the needs of people with severe mental illness have not been represented or included (Jerwood 2016; Shalev et al. 2017).

Since 2013 there has been a Government-led focus on improving the physical well-being of people in the mental health system and in raising the parity of esteem between physical and mental healthcare and associated patient outcomes (Department of Health, Nursing, Midwifery and Allied Health Professions Policy Unit 2016, Royal College of Psychiatrists, 2013). People with long-term mental illness die, on average, ten to twenty years earlier than the general population and experience higher rates of many life-limiting conditions (Department of Health 2013, Department of Health, Nursing, Midwifery and Allied Health Professions Policy Unit 2016, Mental Health Foundation 2008, NHS England 2018). Yet, still little is known about their end of life care needs, and little has been done to try to improve end of life care for this patient group. A summary of policy is included in Chapter 2 (Contextual Background).

The study question arose from clinical observations by the researcher and curiosity about the apparent under-representation of people with long-term mental health conditions receiving end of life care. Despite encountering many patients with very poor physical health in a mental health setting, very few patients with diagnosed mental health conditions appeared to be accessing hospice services. There were a small number of patients who were the exception, and who were referred for art psychotherapy through the hospice as a gateway service, rather than the more usual referral pathway of referral directly to the community nursing team or inpatient unit. These patients were resistant to accessing other hospice services, fearful about how they would be received and also about what the purpose of the hospice referral was. As people with histories of mental ill health, they often had poor experiences of accessing healthcare, but were open to the idea of meeting with an art psychotherapist. Art psychotherapy became the gateway service, and through building a therapeutic relationship which focused on the patient's feelings about their situation and processing the feelings and emotions about receiving a terminal diagnosis, other referrals were able to be made. As a clinician, the researcher became increasingly interested in this patient group and their experiences of PEOLC. This led to some initial investigation in the mental health trust, exploring whether there

was an end of life care policy, and holding discussions with colleagues about their experiences of patients who had serious physical illnesses and terminal conditions. Anecdotal evidence, from within the Trust, highlighted examples of poor practice in relation to patients who developed terminal conditions. Several patients and staff recounted examples of patients being discharged back to their GP from secondary mental health services upon receiving a terminal diagnosis. Other examples included patients with long-term conditions who had been described as “not able to recover” so had no need for secondary mental health support. The recovery agenda which is prevalent in mental health services was cited several times in these early discussions as a barrier to care. In contrast to these accounts were examples of clinicians trying to develop positive relationships with PEOLC services locally and improve care within the Trust, particularly in older adult’s services. However, these endeavours were not co-ordinated, consistent or formalised, so tended to be ad hoc.

At the same time, the end of life care strategy for the city was published (Birmingham South Central CCG & Birmingham Cross City CCG 2014). This was a multi-agency document which outlined a vision for PEOLC for Birmingham. It was a positive document with some coverage of the needs of particularly marginalised groups such as BAME communities, lesbian, gay, bisexual and trans (LGBT) people, people with learning disabilities and homeless people, but again no focus on the specific needs of people with SMI.

This led the researcher to undertake a scoping literature review on palliative and end of life care and the needs of people with SMI, as part of a Health Education England (HEE) National Institute for Health Research (NIHR) Clinical Academic Internship Scheme (Jerwood 2016). This scoping review highlighted an extremely small pool of published research. This led to the development of a research project, conducted as part of an NIHR Master’s by Clinical Research Scholarship at Coventry University, which examined the barriers to delivering end of life care to people with SMI, from clinician’s perspectives (Jerwood et al. 2018). These studies underpinned the research in this thesis. A more detailed summary of previous research is included in Section 2.3 (Summary of Recent Research Projects).

1.3 Researcher Background

Art psychotherapy places the making of images and objects at the centre of the therapeutic relationship between therapist and patient (British Association of Art

Therapists 2018). The use of visual images and of the act of making is an important part of art psychotherapy practice and increasingly, also within research practice (Holliday, Magee and Walker-Clarke 2015, Kara 2015, Mannay 2015). The selection of data collection methods was informed by the researcher's professional practice and the belief that providing additional creative methods, alongside verbal discussion, for participants to share their views and experiences, would add a richness and depth to the data collected, and therefore an added dimension to the understanding of the research topic (Mannay 2015, McNiff 2006, Van der Vaart, van Hoven and Huigen 2018). The researcher's understanding of the power of visual images to evoke emotion and to enhance experiential learning was also evident in the exploration of the nature of the resource developed through the co-design process. Using visual methods to enhance impact was important at all stages throughout the study.

The researcher is an HCPC Registered Art Psychotherapist working in both adult mental health and end of life care. As a clinician, the researcher has always worked with marginalised groups and this thesis is underpinned by a belief in challenging inequality and a desire to improve care for the most vulnerable patients. The research topic was approached from a value base which included challenging discrimination and prejudice and improving care for the most marginalised individuals and groups (Dixon et al. 2015, Reimer-Kirkham et al. 2016, Scullion 2009). Participatory research, particularly co-creation methods, offered an opportunity for patients and clinicians to work together using creative methods, to create the resources which they would use or which would improve the care they receive (Borgstrom and Barclay 2017, Greenhalgh et al. 2016, Palmer et al. 2018, Springham and Robert 2015). The rationale for the methodological choices is discussed in Chapter 4 (Methodology) and Chapter 7 (Discussion).

In addition to the findings of the literature review and previous study of clinician's views, the researcher's professional and personal beliefs and values shaped the decisions behind the choice of approach, methodology and methods. Direct experience of working with patients with mental illness, as they struggled to access the services of the hospice where the researcher was employed, led him to question the quality and provision of PEOLC. As a therapist working with dying people and people with SMI in clinical practice, the researcher felt his clinical experience would support the development of a research study to explore how care could be improved. Having the extensive clinical experience of working in adult mental health services and hospice care enabled the researcher to approach the study with an understanding of the complexities of working with the patient group.

1.4 Patient and Public Involvement in the study

The involvement of patients, carers and other stakeholders, including staff, was central to the development of the research study and so is included at this point as it influenced the development of the study questions and research design.

INVOLVE (NIHR 2018) is a national NHS advisory group that supports patient and public involvement (PPI) in health and social care research. INVOLVE defines public involvement as research being carried out 'with' or 'by' members of the public, rather than 'to', 'about' or 'for' them. This includes patients and their relatives as well as members of the public.

There are three levels of PPI defined by INVOLVE:

- Involvement – where people are actively involved in research projects and in research organisations.
- Participation – where people take part in a research study.
- Engagement – where information and knowledge about research is shared with the public.

(www.invo.org.uk)

Within healthcare more broadly, the principles of service user involvement (SUI) have been recognised for many years (Forrest et al. 2000, Fudge, Wolfe and McKevitt 2008, Hickey and Kipping 1998, Tait and Lester 2005). To differing degrees, SUI in mental health services has moved beyond basic, tokenistic consultation to co-creation and meaningful participation. Although not always carried out effectively in every clinical setting, mental health organisations largely recognise the importance of SUI in developing services (Omeni et al. 2014, Millar, Chambers and Giles 2015). The challenges of representation, for example which patients and carers get involved and how meaningful involvement is, still varies across the health service (Fudge et al. 2008, Tritter and McCallum 2006). In the development of this study, patients, carers and clinical staff (as end users and audience for the findings) were actively sought to be involved at different stages, from research design to participation in data collection through co-design.

As the research topic arose from clinical practice, the research ideas and themes had been discussed informally with patients and staff in different organisations (mental health and PEOLC), and as part of initiatives run locally in organisations for Dying Matters Week. Consultation sessions were conducted as part of the development of an End of

Life Care strategy within the mental health trust where the researcher was employed. The researcher presented the findings of the preceding clinician-focused study at a range of clinical conferences and events and patient and clinicians contributed thoughts and responses, which contributed to the design of this research.

A service-user research group, hosted by a neighbouring University, was approached, where service users with mental health conditions who were experienced in reading research proposals are available for consultation at the early stages of developing the research protocol and ethics applications. However, the group did not have any members who felt they knew enough about issues surrounding PEOLC to be able to look at initial research outlines. This was disappointing but highlighted the issue of the lack of studies concerning palliative and end of life care issues within mental health research.

Coventry University Faculty of Health and Life Sciences had a service user research group (RSVP) who met monthly and who had contributed to the design of the preceding clinician study. The RSVP group again provided helpful feedback on the research design, protocol and materials to support the ethics application. One of the helpful pieces of feedback from the RSVP group was to consider how social media could be used to aid publicity and recruitment to the study, given the participant pool were potentially quite difficult to identify.

The researcher was keen to have patient, carer and clinician input into the research design as all were potential stakeholders and end users. Staff were invited to comment on the research proposal by email, as well as groups of patients via the Mental HealthTrust service user group. The Trust service user group gave particularly useful feedback on the posters and flyers which were used for recruitment, particularly regarding used of language, the style and layout of the posters and locations they should be displayed. It was also suggested by this group that GP practices be used for the circulation of flyers, as many patients engage with their GP's regarding physical health issues and may be more alert to research studies advertised in these settings. An ethics amendment and specific permission was made and granted by the NHS REC and Clinical Research Network to do this (see Appendix 3).

The subsequent research design aimed to ensure that patients and carers were involved not only in the planning and development of the study, and not just as passive research participants to be interviewed, but as active co-creators in the co-design process, a central context for the study (Pearce and The Co-Creating Welfare Team 2018).

1.5 Definitions

There are multiple definitions for both palliative and end of life care and severe mental illness. In addition, the terms co-design, co-creation and co-production are often misunderstood and subject to varying definitions. This is further discussed in Chapter 4 (Methodology). For the purposes of this study the following definitions have been adopted.

1.5.1 Palliative Care

The World Health Organisation defines palliative care as:

> '…..an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual' (World Health Organisation 2017).

Palliative care:

- Provides relief from pain and other distressing symptoms
- Affirms life and regards dying as a normal process
- Intends neither to hasten or postpone death
- Integrates the psychological and spiritual aspects of patient care
- Offers a support system to help patients live as actively as possible until death
- Offers a support system to help the family cope during the patient's illness and in their own bereavement
- Uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated
- Will enhance quality of life, and may also positively influence the course of illness
- Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and include those investigations needed to better understand and manage distressing clinical complications (World Health Organisation 2017).

Palliative care may be provided alongside curative treatment and may be provided throughout the duration of a life-threatening illness. This is distinct from end of life care, which is care specifically focused on the last phase (up to 12 months) of life. For example,

somebody living with a long-term condition, which is incurable, such as multiple sclerosis or cystic fibrosis, may receive palliative care for many years but would only require end of life care in the last phase of life.

1.5.2 End of life Care

> End of Life care *'helps all those with advanced, progressive, incurable illness to live as well as possible until they die. It enables the supportive and palliative care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support.' (Department of Health 2008)*

There is sometimes confusion and overlap between these definitions and they can be used interchangeably. This study has adopted the term palliative and end of life care throughout (PEOLC) as the barriers people with SMI experience occur throughout the stages of care a person diagnosed with a terminal or incurable condition requires from the point of receiving a terminal diagnosis until they die.

1.5.3 Terminal illness or condition

The term terminal illness has been used as an overarching term to describe those conditions which are incurable. Other terms include life-limiting, life-shortening or palliative condition. Patients and carers commented that these terms can be confusing and terminal is a term they felt had broad understanding.

1.5.4 Severe Mental Illness

There are many different definitions of, and ways of categorising, mental illness. This research concerns people with long-term, serious, mental health conditions, being treated within the mental health system. Diagnoses are usually categorised using World Health Organisation's International Classification of Mental and Behavioural Disorders Tenth Revision – ICD10 (World Health Organization 2010) and may include schizophrenia or psychosis, personality disorder, depression and anxiety and bi polar disorders.

A broad definition has been used to define severe mental illness. There are various ways the population could have been described – people with psychiatric diagnoses, secondary mental health care users or people with specific diagnoses, classified in ICD-

10. Using specific diagnoses does not consider the range and variance in diagnosing mental health conditions. Some patients have multiple diagnoses or diagnoses which change during their mental health service journeys. Using secondary mental health care as the criteria may mean the findings are unclear for audiences outside UK healthcare systems, where services are structured differently.

The patients the study concerns are those who have *diagnosed* mental health conditions and who have accessed secondary mental health services, as it is these labels and experiences where the stigma is experienced and where the physical health disparities exist. It was important also, to include those patients with histories of SMI and secondary mental health care use who may be currently cared for in primary care or who have disengaged with secondary mental health services. Therefore, the term SMI has been used throughout.

1.5.5 Informal Care Networks

Members of the patient's informal care network may be family members, friends, neighbours, work colleagues or members of a religious organisation, or any significant people close to the patient and involved in their care and support, who are not paid to do so. It offers a more inclusive definition than carer or family member and acknowledges that support and care networks are complex and varied.

1.5.6 Clinicians and clinical staff

The terms clinician and clinical staff have been used as overarching terms to described professional, paid healthcare staff. This includes medical, nursing, allied health professional and other healthcare staff, such as palliative care assistants, physician's assistants and healthcare assistants.

1.5.7 Co-production, Co-Creation and Co-Design

Multiple definitions of these terms exist and they continue to be used interchangeably in clinical settings (Fox 2018; Sanders and Stappers, 2008; Voorberg, 2015). All refer to the importance of placing the end user, service user and stakeholders at the centre of the collaborative process. For the purposes of this study the term co-creation was used in the literature review as an umbrella term, to encompass the different forms of co-production, co-creation and co-design, used in health settings. Co-creation is defined by Sanders and Stappers (2008) as, 'any act of collective creativity'. Sanders and Stappers (2008) further define co-design as a, 'specific act of co-creation, involving collective

creativity across the design process'. Freire and Sangiorgi (2010) helpfully draw together the following definitions:

- **Co-creation** – places users at the centre of design and implementation, production and continuous development of services
- **Co-production/co-construction** – uses participants' capacities to deliver public services in an equal and reciprocal relationship
- **Co-design** – focuses on generating solutions to problems in partnerships between patients, professionals and community, working together in the design development process

However, the terminology continues to evolve and is used inconsistently in the literature. Co-production tends to focus more on service delivery and co-design focuses on the process of designing and developing services, products or interventions. For the purposes of the literature review, co-creation was used as an umbrella term to describe all the different approaches used in the research evidence, which are then individually specified in the search terms. All co-creation approaches place importance of the involvement of stakeholders, service users and or end users/beneficiaries of the improvement or innovation at the centre of the creative development process. Further discussion of the specific approach adopted for the study, co-design, is included in Chapter 4 (Methodology). A discussion of the interchangeable use of terms is included in Chapter 3 (Literature Review).

1.6 Structure of Thesis

The thesis is structured in a series of eight chapters.

Chapter 1 Introduction includes a brief introduction to the thesis topic and the research area. The research aims are presented and background information to the study and the researcher is outlined. It introduces the structure of the thesis, key definitions and brief summaries of each chapter.

Chapter 2 provides a summary of key policies which provide the context to the study. As the topic of the research is multi-disciplinary and cross-cutting, an overview of key policies and the clinical context is provided. The relationship between poor mental health and poor physical health is explored and located within a policy context. Fear and stigma in clinical practice are explored.

Chapter 3 presents a literature review which explores the use of co-design in mental health services and PEOLC services. The themes from this literature review underpin the major methodological and research questions. The chapter concludes by introducing the research questions, aims and objectives of the study.

Chapter 4 outlines the methodology and research methods chosen. It outlines the research paradigm, epistemology and ontological origins of the study. The methodology is described for each part of the research. The rationale for the methodology is proposed and contrasted with other methods which were disregarded. Data collection methods are described, and the process of data analysis presented. Ethical considerations and approvals are outlined.

Chapter 5 presents the findings of the patient and carer interview stage of the co-design process, within a conceptual framework, including four overarching themes illustrated with quotes from the original interview transcripts.

Chapter 6 presents the findings of the workshop stage of the co-design process. The themes from the workshops are presented and illustrated with photographs of the artefacts produced. The proposed resource concept is presented.

Chapter 7 discusses the findings from the study and addresses each of the research questions. The original contributions to knowledge are identified. The limitations of the study and reflections on the methodology and quality of the study are discussed. Personal reflections on the research journey are also included.

Chapter 8 presents the conclusions, key messages from this study and outlines the implications and recommendations for clinical practice and further research.

1.7 Chapter Summary

This chapter has introduced the topic and aims of the study, the background to the study and has described the researcher's background and experience. The structure of the thesis is presented and the key definitions to terms are outlined. The next chapter explores the contextual background to the research, outlining key policies and clinical context. Concepts of fear and stigma in a clinical context are explored.

Chapter 2 Contextual Background

This chapter outlines the wider contextual background to the research thesis and summarises previous research carried out by the author, as part of a preceding Masters by Clinical Research, which informed the design of this study. The chapter begins with a summary of the policy context the research is located within. As the research was located in a multi-disciplinary context incorporating palliative and end of life care and mental health care, a summary of relevant policy across the specialisms is included.

The research explored in this thesis was carried out between September 2016 and September 2018. Prior to this study, two preceding stages of the research had been carried out and the second stage was subsequently published in the European Journal of Palliative Care (Jerwood 2016; Jerwood et al. 2018). The first was a literature review exploring the barriers to delivering PEOLC to people with SMI and the second was an empirical study exploring the views and experiences of mental health and palliative care clinical staff on providing palliative and end of life care for people with SMI. The findings of these studies form part of the background to this research study and are summarised later in this chapter in Section 2.3 (Summary of Previous Research Projects).

A key finding in these studies was that the lack of confidence of clinical staff, and their underlying fears and prejudice towards mental illness, death and dying, are a key barrier to providing PEOLC to people with SMI. Therefore, a discussion of the fear and stigma surrounding mental illness, death and dying and the significance of this in healthcare settings concludes the chapter.

2.1 Policy and Strategic Context – Mental Health

This research was carried out against a policy backdrop which brings both mental health and PEOLC to the forefront of health policy (All Parliamentary Group on Mental Health 2013; Department of Health 2008; Department of Health 2013; Department of Health, Nursing, Midwifery and Allied Health Professions Policy Unit 2016; Hospice UK 2013; Mental Health Taskforce 2016; National Institute for Clinical and Healthcare Excellence 2017; National Institute for Health Research 2018; National Palliative and End of Life Care Partnership 2015; NHS England 2018; Royal College of Psychiatrists 2013). Both areas of health provision, have at different times, been described as ‘Cinderella’ services (Jones-Berry 2017; Mitchell 2013; Spandler and Stickley 2011; Stevens et al. 2007; Turner-Stokes, Sykes and Silber 2008) somewhat separate or marginalised in

comparison to other health specialities. The policies summarised in this chapter illustrate how the focus has increased in recent years on both areas of clinical practice.

2.1.1 Mental Health Policy in the UK

In 2018 the Government published a briefing paper 'Mental health statistics for England: prevalence, services and funding' (Baker 2018). A survey of adult mental health is carried out every seven years; this paper reports on the most recent Adult Psychiatric Morbidity Survey which was carried out in 2014 and released in 2016. This report is the most recent assessment of prevalence of mental ill health conditions in the United Kingdom (UK) and includes some data about the physical health conditions people with mental ill health also experience. One in six people aged 16+ reported having symptoms of a Common Mental Disorder (CMD) in 2016/17. CMD is a definition which incorporates some of the conditions which would fall under the label of SMI and include conditions such as depression, anxiety, panic disorder, phobias and obsessive-compulsive disorder. In addition, 2% of adults screened positive for bipolar disorder, 0.7% of adults were assessed as having a psychotic disorder (Baker 2018). Over a third (37%) of people with severe symptoms of CMD reported having physical health conditions such as high blood pressure, asthma, cancer, epilepsy. Many people with CMD are supported in primary care and access psychological support via the Improving Access to Psychological Therapies programme (IAPT). In 2016/17 there were 1.4 million referrals for talking therapies through IAPT (Baker 2018). People with more severe symptoms of CMD or more serious mental illnesses are supported in secondary mental health services in the UK.

Just over two million adults (1 in 21) with SMI were in contact with specialist mental health care at some point during 2016/17 and just under 46,000 were detained under the Mental Health Act (Baker 2018; NHS Digital 2018). Of those adults with SMI, 90% are supported by community services. 20% of people on the Care Programme Approach (for people with more severe or complex needs) had not had a formal meeting to review their needs in the previous 12 months (Mental Health Taskforce 2016). This is interesting because anecdotal evidence and the previous literature review indicates poor care co-ordination is a key barrier to providing effective PEOLC to people with SMI. Approximately half a million people die each year in the UK (0.77 of the population), which would mean at least 15,400 people in contact with specialist mental health services die each year in the UK (Office for National Statistics 2017). This does not consider the higher mortality rate of people with SMI so is likely to be an underestimation

of potential numbers of patients dying whilst accessing specialist mental health services. However, it provides a sense of how many people may be affected by poor access to PEOLC. A recent report (Murtagh et al. 2014) reported that up to 80% of patients who die would benefit from palliative care. Patients with SMI, who may have less family support and greater social and economic inequalities (Department of Health, Nursing, Midwifery and Allied Health Professions Policy Unit 2016; NHS England 2018; Royal College of Psychiatrists 2013) are likely to benefit from PEOLC even more than the general population (Mental Health Foundation 2008; Woods et al. 2008).

2.1.2 Mental Health and Physical Health

Adults with long-term mental illness die on average 20 years earlier than the general population (Brown et al. 2010; NHS England 2018). Early mortality in people with SMI is mostly due to preventable causes and is one of the biggest health inequalities in the UK (NIHR 2018). Approximately 60% of excess mortality can be attributed to preventable physical conditions (NIHR 2018) such as diabetes, heart, lung and infectious diseases. This has led to a focus on improving the physical health of people with SMI (NHS England 2018).

People with mental ill health are more likely to live in poverty, find it harder to find and stay in employment, are more likely to live in poor housing or be homeless and are more likely to have poor physical health which is due in part to higher rates of smoking, alcohol and substance use and poor diet (Department of Health, Nursing, Midwifery and Allied Health Professions Policy Unit 2016; NHS England 2018; Royal College of Psychiatrists 2013).

There are a range of other factors which mean that people with mental ill health receive diagnosis of physical health conditions later than the general population and therefore often have poor prognosis, difficulties accessing GP services, communicating symptoms, lack of trust and not being taken seriously by healthcare staff (Royal College of Psychiatrists 2013). Physical symptoms are often dismissed as mental health issues. This is known as ‘diagnostic overshadowing’ (Noblett, Lawrence and Smith 2015). Poor mental health can impact upon a person’s ability to look after their physical well-being and seek treatment for physical health problems (ReThink Mental Illness 2012).Therefore, it would be expected that a higher rate of people with SMI would need PEOLC services (Woods et al. 2008; Terpstra and Terpstra 2012) due to later diagnosis and poor management of physical health conditions. People with SMI have often also

had negative experiences in healthcare settings which may make them more reluctant to seek preventative and screening services (Mental Health Foundation 2008; Woods et al. 2008).

Whilst it is right to focus on the preventable elements of poor physical health, and to improve physical health, and better understand the relationship between improved physical health and improved mental health, it is still necessary to focus on improving access and quality of PEOLC for people with SMI who do develop terminal conditions (Shalev et al. 2017; Stajduhar et al. 2019; Webb et al. 2018). They still have the same rights as the rest of the population to make empowered, informed choices about PEOLC, to be treated with respect and dignity and to receive timely and appropriate care until the end of their lives (Stajduhar et al. 2019).

One of the unexpected negative outcomes of the recovery focus in mental health is the lack of focus on ageing, long-term physical conditions, palliative and end of life care needs of people with SMI (Slade et al. 2014). Considerations of death and dying in mental health tend to focus on prevention of suicide (ReThink Mental Illness 2012). This comes at the expense of people who have incurable long-term conditions who may not 'recover' from their mental ill health. As recently as 2017, there were anecdotal accounts shared with the researcher of patients diagnosed with terminal conditions being discharged from secondary mental health care without discussion or consideration of their potential mental health needs to the end of life, or the needs of other agencies who may become involved.

2.1.3 Parity of Esteem

The Royal College of Psychiatrists report '*Whole person care: From rhetoric to reality: Achieving parity between physical and mental health'* (Royal College of Psychiatrists 2013) outlines how parity should be achieved between physical and mental health services and included ambitions relating to equalising life expectancy and improving physical healthcare services for people with SMI.

Achieving parity of esteem between physical and mental health services became a key priority for NHS England in 2013 (All Parliamentary Group on Mental Health 2013; Department of Health 2013; Royal College of Psychiatrists 2013) and has focused on improving the disparities between physical and mental healthcare services and funding, and also improving the opportunities for people with mental illness to access good physical health care services, including end of life and palliative care, where appropriate.

The All-Parliamentary Group on Mental Health (All Parliamentary Group on Mental Health 2013) identified that people with long-term mental health problems typically have less choice of services and less control over the kind of support they need and this is also the case in relation to accessing PEOLC (Mental Health Foundation 2008). Improving access to physical health checks for people with SMI has also been incentivised under the Quality and Outcomes Framework (QOF) and supported by the publication of recent guidance (Mental Health Taskforce 2016; NHS England 2018; Working Group for Improving the Physical Health of People with SMI 2016).

Of relevance to this study are two specific ambitions:

> *'people with mental health problems will receive the same quality of physical healthcare as those without a mental health problem'*
>
> *'people with mental health problems will express the same levels of satisfaction with their health and social care services as people with physical health conditions, including the same levels of dignity and respect from health and social care staff'* (Working Group for Improving the Physical Health of People with SMI 2016:17).

This is currently far from the case for people with SMI and terminal health conditions (Jerwood 2016; Mental Health Foundation 2008; Shalev et al. 2017; Woods et al. 2008).

'Improving the physical health of adults with severe mental illness: essential actions' (Department of Health, Nursing, Midwifery and Allied Health Professions Policy Unit 2016) was published by the Department of Health and developed by an intercollegiate working group of eight medical and nursing colleges in 2016[2] and outlines recommendations for the commissioning and provision of physical healthcare for people with SMI, including more coverage across core training of mental and health conditions. This highlights the policy level understanding of the lack of training and competency in healthcare staff with regard to working with people with mental ill health. This lack of training and clinical confidence was highlighted in the findings of the previous underpinning study by the researcher (Jerwood et al. 2018). Improving clinical confidence is a key aim of this study.

[2] Royal College of Psychiatrists, Academy of Medical Royal Colleges, Royal College of Pathologists, Royal Pharmaceutical Society, Royal College of Physicians, Royal College of General Practitioners, Royal College of Nursing, Public Health England

2.1.4 The Five Year Forward View for Mental Health 2016

> *'For far too long, people of all ages with mental health problems have been stigmatised and marginalised, all too often experiencing an NHS that treats their minds and bodies separately. Mental health services have been underfunded for decades, and too many people have received no help at all, leading to hundreds of thousands of lives put on hold or ruined, and thousands of tragic and unnecessary deaths.'* (Mental Health Taskforce 2016:3).

The Five Year Forward View for Mental Health (Mental Health Taskforce 2016) was published by an independent mental health taskforce in 2016 and sets out a series of recommendations for the NHS to prioritise services for people living with SMI by 2020/21. Improving the physical healthcare of people with mental ill health and treating mental and physical health in a more integrated way are key priorities in the plan. The *Forward View* rightly focuses on prevention, early intervention and improving mental and physical health. However, this should not be at the expense of thinking about improving the quality of life of people with mental illnesses throughout the life course. Issues surrounding the ageing mental health population, supporting people into old age, increases in numbers of people with dementia and supporting people with longer-term, chronic and terminal conditions are given little or no attention.

2.1.5 Mental Health Research

In March 2018, NIHR published *'Forward Thinking: NIHR research on support for people with severe mental illness, a themed review of recent research'* (National Institute for Health Research 2018). Thirty studies funded by NIHR and carried out since 2005 are included in the review. Recent research is presented under the following categories: early detection and intervention, crisis care, stabilising mental and physical health, supporting recovery and looking ahead. Once again, research about the latter stages of life, ageing, dying or managing co-morbid terminal conditions is not included. This highlights the lack of research overall which concerns death, dying and the end of life for people with SMI. One of the aims of this study is to contribute new findings to address this lack of research.

The NIHR review paper has limited definition of SMI and focuses mainly on psychosis. Other mental illness and psychiatric diagnoses such as depression, bi-polar disorder and personality disorders are common diagnostic labels for people in secondary mental

health services (Baker 2018; NHS Digital 2018) but are not included. Stigma towards people with mental illness does not focus solely on people with schizophrenia and psychotic type illnesses. Therefore, a broader definition of SMI has been used for this study. The stigma towards mental illness per se, not just to specific psychiatric labels, is a major contributing factor to barriers to care or poor care delivery (Bates and Stickley 2012; Knaak, Mantler and Szeto 2017; Robson and Haddad 2012; Stadjuhar et al. 2019).

This section has summarised some of the key mental health policies which are relevant to the background to this study. The next section outlines some of the key PEOLC policies which also form part of the contextual background to the study.

2.2 Policy and Strategic Context: Palliative and End of Life Care

Much of the confusion relating to PEOLC lies in it being misunderstood as only care needed in the last days or weeks of a person's life or care which people who have cancer require (Hospice UK 2013; Marie Curie 2016; Shalev et al. 2018). It is important to define what is meant by PEOLC within the context of this thesis as multiple definitions exist (see Definitions in Section 1.3).

The term 'palliative and end of life care' (PEOLC) is used as an umbrella term throughout because to use one term (just palliative care, for example) may imply the other is excluded. The term 'terminal illness' is used in response to feedback from the patient consultation group (RSVP) who felt it was a well understood term by patient and carers, as opposed to other terms such as life-limiting, life-shortening or palliative condition. In fact, the thesis aims are concerned with the care that people with SMI require from the point of diagnosis of a condition that is not curable, and which will shorten a person's life. The stigma experienced by people with SMI is apparent in all areas of care delivery (Mental Health Foundation 2008; Woods 2008), not just specialist palliative care and as discussed, PEOLC may be provided by many different professionals and agencies in different settings (Hospice UK 2013; Marie Curie 2016).

People with SMI and terminal conditions come into contact with multiple organisations and professionals including, but not exclusively:

- mental health trust community care co-ordinator (usually a community psychiatric nurse but sometimes a social worker)
- in-patient key worker (usually a member of ward staff)

- psychiatrist responsible for overseeing mental health care diagnosis, care and treatment
- GP
- practice nurse or district nurse;
- hospital specialists such a condition-specific consultant and their teams,
- hospice staff, community or hospital palliative care teams, social care or care staff in the community,
- charitable or voluntary sector agencies (may be condition specific).

Some agencies may be exclusively providing PEOLC such as a hospice or community palliative care team. Other agencies may be providing other types of care, but this does not mean they are not also providing PEOLC, for example, a GP practice or hospital team providing condition-specific care (Hospice UK 2013). Mental health services, whether they are NHS or voluntary and community sector–based, primarily support recovery from mental illness and long-term support for those who may not recover. However, they are also required to provide PEOLC, either directly, or through co-ordinating care with other agencies (National Palliative and End of Life Care Partnership 2015). Their primary involvement is with somebody's mental health condition, but when a person also has a terminal, incurable or progressive condition, it is not possible to solely treat a patient's mental ill health, without engagement in their physical health conditions and the relationship between the two.

2.2.1 End of Life Care Strategy 2008

The national *End of Life Care Strategy* (Department of Health 2008) aimed to improve the provision of care to all people at the end of their lives. It identified some significant issues affecting death and dying in England. Many people do not die in the place they would choose and many people do not receive quality care at the end of their lives and some are not treated with dignity and respect. The strategy states that in the past the profile of PEOLC has been low, leading to variability in access and quality across England and within different communities (Department of Health 2008).

The strategy introduces the concept of a 'good death' and acknowledges that there are many challenges to overcome before this is a reality for everyone irrespective of their background. The features of a good death are described as:

- Being treated as an individual, with dignity and respect
- Being without pain and other symptoms

- Being in familiar surroundings
- Being in the company of close family and/or friends

A review of literature carried out by the Mental Health Foundation (Mental Health Foundation, 2008) highlighted the barriers to care which are experienced by people with SMI and called for further research to be carried out into the PEOLC needs of people with SMI. A subsequent review carried out by the researcher (Jerwood 2016) highlighted that despite urgent calls for further research in previous reviews, little or no research had been carried out since the publication of the MHF review or the publication of the End of Life Care Strategy. Both reviews describe the barriers which lead to people with SMI being less likely to receive the care that would lead to a 'good death'.

2.2.2 End of Life Care NICE Guidelines

In 2011, updated in 2017, The National Institute for Health and Care Excellence (NICE) published a set of quality standards (NICE 2017) to support the delivery of the aims of the End of Life Care Strategy. These standards incorporate all aspects of end of life care including assessment, psychological support, care co-ordination, urgent care, specialist palliative care and bereavement care. In addition, and relevant to this research, it also includes a quality standard for workforce training, which outlines the training and education staff should be able to access to ensure they can provide good care to all patients. The quality standard for end of life care for adults states that 'people with advanced life threating illnesses and their families should expect good end of life care, whatever the cause of their condition' (NICE 2017:2). Clearly there are significant barriers, highlighted by the summary of mental health policy in the previous section, for people with SMI in accessing healthcare services and this would include PEOLC (Shalev et al. 2017; Stajduhar et al. 2019).

2.2.3 Ambitions for Palliative and End of Life Care (2015-2020)

In 2015, The National Palliative and End of Life Care Partnership published the *'Ambitions for Palliative and End of Life Care: A national framework for local action'* (National Palliative and End of Life Care Partnership 2015). The partnership consists of organisations representing health and social care, including NHS England, statutory and voluntary bodies, and people with personal and professional experience. The six ambitions are as follows:

1. Each person is seen as an individual
2. Each person gets fair access to care

3. Maximising comfort and well-being
4. Care is co-ordinated
5. All staff are prepared to care
6. Each community is prepared to help

The Ambitions form the basis for the work of all the partner organisations including NHS England and present challenges for care providers and communities in relation to improving care for all, but there are challenges when considering how to achieve these ambitions for people with SMI who require PEOLC. This study aims to provide findings which contribute to the achievement of ambitions 1-5 by highlighting the views and experiences of patients and carers for the first time and developing a resource which aims to improve clinician confidence by addressing some of the fear and stigma surrounding people with SMI. If staff feel less fearful, more confident and empowered, and have access to information, guidance on good practice regarding the care and support needs of people with SMI in PEOLC, then service providers will be better able to achieve these ambitions for people with SMI.

The ambitions are underpinned by eight foundations:

1. Personalised care planning
2. Shared records
3. Education and training
4. 24/7 access
5. Evidence and information
6. Involving, supporting and caring for those important to the dying person
7. Co-design
8. Leadership

(National Palliative and End of Life Care Partnership 2015)

The research design for this study used co-design to ensure that the end users of the resource, and those it affects were involved in the development of the content and format of the resource. The benefits of co-design are discussed in Chapter 3 (Literature Review) and Chapter 4 (Methodology). The aim of the resource is to support staff to better address these eight foundations, particularly personalised care planning, education and training, evidence and information and support to the dying person with SMI and those who care for them. If patients with SMI are to have opportunity to have honest and well-informed conversations about death and dying, then clinical staff must feel confident to approach these topics with them. Clinical staff have highlighted their own concerns and fears about doing this with people with SMI (Bloomer et al. 2013; Candilis et al. 2004;

Foti et al. 2005; Jerwood et al. 2018; Sweers et al. 2013). Any resource developed must address these concerns if this ambition is to be achieved for this patient group.

2.2.4 Research Priorities in Palliative and End of Life Care

The Palliative and End of Life Care Priority Setting Partnership (PeolcPSP), supported by the James Lind Alliance, published the top ten priorities for research in PEOLC in 2015 (PeolcPSP 2015). Whilst understanding the needs of people with long-term mental health problems is not cited within the top ten priorities, adequate staff training to deliver PEOLC, no matter where it is being delivered, is one of the top ten priorities. Other relevant priorities include improving access to end of life care for everyone, improving advanced care planning, out of hours care, improving continuity of care at the end of life and improving end of life care for non-cancer diseases (PeolcPSP 2015). In addition, improving care co-ordination, training and staff support, managing distress and improving access to hospice care are also pertinent to this study and apply to people with SMI and palliative care needs, as well as the general population. It is perhaps also relevant that the needs of people with long-term or pre-existing mental illness were not highlighted within the listed priorities, when other marginalised groups, were included.

2.2.5 Improving access to hospice care

The majority (75%) of community palliative care services are provided by hospices in the UK (Hospice UK 2013). Historically, patients with cancer and in the last weeks of life have formed most hospice referrals (Allsop et al. 2018; Hospice UK 2013; Marie Curie 2016). The public perception of hospice care is of in-patient care of dying patients in the last few weeks or days of life. In 2017, Hospice UK launched a campaign to increase awareness of hospice palliative care. The aim was to break down the myths about hospice care and increase awareness of the breadth of hospice services and PEOLC such as hospice at home, day hospice, bereavement care and psychological support. There has also been a focus on earlier referrals to palliative care to maximise the benefit of these services. Allsopp et al.'s study (2018) found that the average referral for hospice-based palliative care for the general population was less than 7 weeks before death. 40% were referred less than 30 days before death (Allsopp et al. 2018). The study highlights that despite an increased focus on earlier referrals, there is still much to do to ensure that the general population benefit from all that hospice-based palliative care offers, and this is all the more the case for marginalised groups. As highlighted in published literature and policy, people with SMI experience even more barriers to

accessing PEOLC so are even less likely to be referred, even at short notice (Bloomer et al. 2013; Geppert et al. 2011; Terpstra and Terpstra 2012; Terpstra, Williamson and Terpstra 2014).

In 2015, a report *'Equity in the Provision of Palliative Care in the UK: A Review of Evidence'* was published (Dixon et al. 2015) which examined inequities in access to and provision of PEOLC. Several factors such as diagnosis, age, ethnicity, marital status (or having a partner) and sexual orientation were considered in relation to end of life care quality. The needs of people with long-term mental health conditions were not addressed in this report, despite clear findings in the MHF review (Mental Health Foundation 2008) which called for further research to be carried out urgently.

This section outlines the key policy areas which provide the backdrop to the study. Despite increased attention being paid to the physical health of people with SMI, and an increased focus on improving access to PEOLC, the needs of people with SMI at the end of their lives continue to be ignored at a policy and strategic level (Jerwood 2016; Shalev et al. 2017; Stajduhar et al. 2019). The next section summarises the previous research which was carried out by the researcher which add further contextual background to the study.

2.3 Summary of Previous Research Projects

Two previous studies by the researcher, carried out prior to this project have informed the research design and methods. This section describes the key findings from each and form part of the contextual background to this study.

Firstly, a systematized literature review (Jerwood 2016) revealed a limited pool of published research concerning the PEOLC needs of people with SMI. What literature exists originated from outside the UK and did not concern current clinical practice. The literature identified the need for further research to be carried out and comprised some empirical research studies, but mainly included discussion pieces, case studies and retrospective studies and highlighted the problems of providing care to the patient group. There were very few studies which trialled or piloted new approaches to care.

The findings of the literature review informed an empirical study (Jerwood et al. 2018) carried out as part of a Masters by Clinical Research, funded by a Health Education England (HEE) and the National Institute for Health Research (NIHR) award. The Masters study explored the views and experiences of clinical staff on the end of life care needs of people with severe mental illness, barriers to providing good care and views on

how care could be improved. The findings of the study mirrored those in the literature review calling for further research into the end of life care needs of people with mental illness and highlighting the absence of the voice of patients, and their carers, in the published research. This thesis sought to address this gap through including patients with both SMI and terminal conditions, and their carers, in the co-design process in the interview and workshop stages.

A key finding of this study (Jerwood et al. 2018) was the lack of *confidence* that clinicians felt when working with people with SMI who have terminal diagnoses. The lack of confidence was found in both mental health clinicians and PEOLC clinicians. Clinical staff reported feeling confident in their practice when working within their own specialism, however, both groups of clinicians highlighted a lack of confidence, and some underlying fears, when encountering patients with SMI and terminal physical conditions. The study highlighted that clinical staff felt concerned about having conversations about death and dying, out of fear of upsetting or destabilising vulnerable patients. This fear led staff to avoid having conversations about end of life care and decisions, and, it could be argued, to poorer clinical practice.

PEOLC staff were aware of a degree of prejudice and stigma towards patients with mental health diagnoses at the point of referral, and their sense of what they may be able to offer these patients. This feeling persisted beyond the point of referral and into the face to face contact with patients. Clinicians reported feeling under-confident in dealing with unusual beliefs and behaviours, concerns about approaching advance care planning and end of life discussions, especially with patients with previous suicidal feelings. Mental health clinicians experienced a similar lack of knowledge and confidence, but also more of a resistance to delivering end of life care within their role. This was particularly the case with community mental health staff. Within in-patient and residential settings, particularly in older adult services, there was less resistance to delivering PEOLC, but all clinicians felt that the mental health trust services where not equipped to meet the physical healthcare needs of terminally ill patients.

Both groups of clinicians reported a need for information, guidance and best practice in an easily accessible form. The lack of time and budget for training courses was highlighted as a barrier to gaining this knowledge. Clinicians also reported examples of times where they felt they had provided good care but added caveats that this often felt like bending or breaking the rules or normal clinical practice. This was not identified by clinical staff as individualised care planning, or person-centred care, but something to be

kept hidden or apologised for. Both groups of clinicians also commented that patients with SMI and terminal conditions were not great in number in their individual clinical settings, but that when they did encounter them, they caused high levels of professional anxiety, mainly due to not feeling sure about how best to meet the patient's specific needs. Coping with this anxiety led to the perception that these patients are resource intensive.

Other themes were identified such as a lack of partnership working and the prevalence of 'silo' working across the health system. Mental health and physical health services are commissioned and delivered as two separate systems. Within both, there are further sub-specialisms. This creates professional divisions for clinicians and divided services for patients. This is exacerbated by the services who are responsible for care co-ordination, such as GPs and mental health care co-ordinators, being so stretched that they have little time and are often responding to an immediate crisis, rather than being able to provide holistic, care co-ordinated services which focus on the whole person.

Longer term recommendations focused on creating a more coherent, person-centred health care system where mental and physical health services are jointly commissioned and co-located. Recommendations also included increasing content on core professional training of mental health and end of life care staff. However, following the recommendations that services should be jointly commissioned, co-located, and that training be more holistic, has highlighted numerous challenges including increasing financial pressures in the health service, political direction, resourcing and long-held training structures which separate mental and physical healthcare specialisms.

Even if these challenges could be overcome, if individual members of staff do not feel confident, no amount of restructure or reorganisation will address barriers to care. If clinical staff could be supported to feel more confident in their clinical practice, develop additional skills and knowledge they need to better support people with SMI, then care will be improved. Training, both pre-qualification and continuing professional development (CPD) often focuses on competencies. However, feedback from clinical staff focused on confidence, and wanting a degree of professional autonomy, rather than specific competencies. The need to break down stigma, fear and prejudice about both dying patients and patients with mental illnesses was highlighted. This goes beyond providing knowledge and information. When clinical staff felt they had provided good care, in addition to a sense of 'breaking the rules' they mentioned getting to know the individual patient. For example, where a patient had attended a day hospice service for

a period before being admitted as an inpatient, clinical staff felt more able to have conversations about advance care planning and the patient's needs directly with the patient. This led to considerations of how patient's stories could be told to help clinicians see the individuals behind the labels.

2.4 Fear and Stigma in Clinical Practice

> 'Stigma is a societal creation which has come to describe prejudice and discrimination' *(Corrigan and Rao 2012:468)*.

Following the identification of clinical confidence as a barrier and understanding that underpinning fears and prejudice inform clinical confidence, it is useful to turn to the published literature surrounding perceptions of mental illness, death and dying. The next section explores the fear and stigma surrounding these human experiences and how they inform clinical practice and clinician perceptions of patients.

2.4.1 Mental Illness

Stigma towards people with mental illness dates back to the earliest of records. References to negative stereotypes of people with mental illnesses are evident in ancient Greek writings (Arboleda-Flórez 2003). The perception of mental illness as a punishment from a God for sin is evident within Christian history and the perception of those with mental ill health as being possessed or linked to the devil are prevalent in many religious communities and societies across the world. The separation of the mentally ill, which arguably is still evident in the commissioning and provision of today's mental health services, dates back to the concept of the asylum (Rossler 2016). People with mental illnesses (or what was understood to be mental illness at that time) were taken away, separated, locked up, with the aim of protecting society from them (Arboleda-Florez 2003; Overton and Medina 2008; Rossler 2016).

Fear of people with mental illness comes from two places; fear of physical attack, which comes from fear of the unusual behaviours or beliefs people can have when acutely mentally unwell and fear of contamination that somehow, the mental illness or distress will be spread, caught or passed on (Stuart and Arboleda-Flórez 2001). Although now clinical practice focuses on detaining those who may be a risk to themselves, the risk to others is still a key motivating factor in mental health act assessment. Indeed, sometimes people are very unwell mentally and behave in ways which are risky and intimidating to those around them. However, most people living with mental illness pose no risk to

themselves or to society (Bates and Stickely 2012; Corrigan and Rao 2012; Knaak, Mantler and Szeto 2017). Even though contemporary understanding of mental illness in clinical practice has evolved a long way from these understandings, the stigma which surrounds mental illness continues to be very powerful both in society and in healthcare settings. Most people's contact with people with mental illness is through indirect means (Overton and Medina 2008), through portrayal on television, in films, through newspaper and news accounts. These portrayals are largely negative and focus on danger or threat from the person with mental illness, whether that be the reporting of the rare occurrences where someone with a mental illness hurts a member of the public, or in creating fear and tension in films and television dramas (Arboleda-Flórez 2003).

People living with mental illness experience stigma, prejudice and discrimination in all areas of society. Corrigan and Rao (2012) helpfully describe the differences between different forms of stigma. The paper distinguishes between external, public, stigma experienced by people with mental illness from others; and internal stigma or self-stigmatizing, behaviours which people with mental illnesses inflict upon themselves in response to negative stereotypes and discrimination. Stereotypes are ways of categorising groups of humans, usually by a shared or common characteristic and attributing qualities and traits to that group. Negative stereotypes lead people to develop beliefs about groups of people and these beliefs cause emotional response, often fear, which is when stigma becomes prejudice. The action this fear leads to is discrimination. Living with this discrimination can lead to self-stigmatizing by the person with a mental illness (Baker and Stickley 2012; Corrigan and Rao 2012).

In healthcare settings, groups of patients who don't fit into perceived norms can be challenging to deal with (Conway 2000; Feeley et al. 2013; Knaak, Mantler and Szeto 2017). People with mental illness sometimes present differently to other people, they may show their distress more, they may be angry, they may have unusual beliefs or behaviours, particularly when acutely mentally unwell. In busy, pressurised services, this can be difficult for healthcare staff to cope with. Healthcare staff are subject to the same portrayals of mental illness as the general population and will hold the same fears and prejudices unless they have been exposed to education, training and personal experience which has challenged these stereotypes and prejudices (Knaak, Mantler and Szeto 2017; Overton and Medina 2008; Ross and Goldner 2009).

2.4.2 Stigma in clinicians

In recognition of the fact that clinical staff are not immune from these experiences of prejudice and discrimination, both personally and/or professionally, all professional training programmes for health professionals include content about anti-discriminatory practice. Anti-discriminatory and equalities principles are also enshrined in legislation such as the Equality Act 2010 and the Human Rights Act 1998. However, this does not ensure that all patients are treated equally and there are groups of patients who receive less favourable treatment than others. People with SMI are clearly disadvantaged in healthcare (Royal College of Psychiatrists 2013; Rethink 2012; NHS England 2018; Knaak, Mantler and Szeto 2017) and it is helpful to understand why some patients are more difficult for clinicians to work with than others.

Much of the literature about mental illness and stigma focuses on what the mentally ill person can do to overcome stigma and self-stigma and what society needs to do (Baker and Stickley 2012; Knaak, Mantler and Szeto 2017; Ross and Goldner 2009; Stajduhar et al. 2019. Little appears to have been written about the process of changing views and attitudes within individual clinicians, which is what this resource aims to do. Understanding how an individual clinician can come to feel differently about the patient in front of them is crucial to the improvement of care for this patient group. However, healthcare professionals are also people and their views are reflective of prevalent views in society. Most people enter care professions to help and to make things better for patients but some groups of patients are difficult to work with. Training courses also provide skills such as working with challenging behaviour and advanced communication skills but the underlying prejudice towards mental illness, the fear of mental illness is difficult to overcome even for mental health specialists.

In the seminal research study, The Unpopular Patient (Stockwell 1972), Felicity Stockwell explores whether some patients are more enjoyable, and some less enjoyable to care for, and more importantly, whether this impacts on care. Although not explicitly asking about patients experiencing mental illness and how clinicians respond to caring for people with histories of mental illness, the paper defines characteristics which cause patients to be characterised as popular and unpopular. Stockwell's hypothesis is that there are observable and measurable differences in the nursing care given to popular and unpopular patients.

The characteristics identified by Stockwell feel somewhat outdated now. Initial factors identified included age, religion, nationality and social class. Stigmas mentioned include

disfigurement, blindness and deafness, obesity, aphasia, dysphasia, confusion and incontinence. Patients in need of psychiatric treatment were not included in the initial stages of the study but were added later. Some of the conditions described would now be understood differently, and legislation protects some patient groups now which would not have existed when the paper was written (Disability Discrimination Act 1995; Equality Act 2010).

Stockwell's paper has multiple findings and has been used extensively in nursing education since it was written (Conway 2000; Johnson and Webb 1995). Its significance to this research is that it states in its conclusions that none of the 29 patients classified with a psychiatric diagnosis were placed in the popular category. Half were rated as neutral and half as unpopular. Other patient groups which were classified as unpopular were 'foreign patients' and those with long stays (over 3 months). Understanding of race, ethnicity and culture have evolved significantly since the 1970's (Johnson and Webb 1995) and patients would not be now classified as 'foreign'. Hospital stays for many patients are shorter now due to advances in technology and medical procedures, care at home and community nursing. Patients who were perceived to be cheerful and wanting to help themselves were perceived to be popular. Living with a long-term mental illness, and being subject to discrimination, are both factors which may mean patients with psychiatric diagnosis were not perceived as cheerful, may not communicate in the same way as other patients and may not have the same perceived motivation to 'help themselves'.

The significance is Stockwell's paper to this study is two-fold. A key finding in her paper was that nurses ranking of what they enjoyed about working with popular patients was not based upon nursing tasks, but in how well they related to the patient and if they 'got on'. Patients with psychiatric diagnosis, and patients with behaviours which would be understood as related to personality difficulties and 'not fitting in' were classified as unpopular. Stockwell's paper concludes, significantly, that patients classified as unpopular, are not as enjoyable to look after.

It would be easy to assume that attitudes have evolved since Stockwell's paper was published. Certainly, legislation and policy have added protection from discrimination for groups of patients including those with a disability or long-term health condition. Attitudes to mental illness have certainly moved forward in some spheres, in part due to campaigns by people in the public eye such as Ruby Wax and Alistair Campbell and Government campaigns such as Time to Change (http://www.time-to-change.org.uk

2018) have also attempted to de-stigmatize mental illness. However, stigma still exists and several more recent studies of healthcare professionals highlight ongoing issues in the care of people with mental illness both in general healthcare and mental healthcare (Baker and Stickley 2012; Brinn 2000; Knaak, Mantler and Szeto 2017; Stajduhar et al. 2019).

More recently, Brinn (2000) carried out another study of the attitudes of general nurses to patients with mental illness. Brinn's study found that registered nurses (RN's) were fearful of people with a mental health problem and wary of possible unpredictable behaviour. Brinn states that nurses with more exposure to people with mental ill health in their training felt more confident in working with these patients. Since the paper was published, it would be expected that inclusion of working with patients with mental health difficulties had increased in nursing training programmes, however, studies carried out more recently indicate that more is still to be done to challenge prejudicial attitudes to mental illness in nursing (Conway 2000; Robson and Haddad 2012).

It is not just within the nursing profession that stigma towards patients with mental illnesses is still prevalent. In a more recent study (Noblett, Lawrence and Smith 2015) the attitudes of general hospital doctors towards patients with comorbid mental illness are explored. The researchers used vignettes to assess respondent's attitudes towards eight patients presenting with a physical complaint and different clinical histories including personality disorder, schizophrenia and depression as well as non-mental health difficulties or characteristics such as diabetes and 'being a Christian'. The results of the study indicate that negative views of people with mental illness continue to be prevalent among general health professionals.

In addition, Noblett, Lawrence and Smith (2015) highlight the link between negative attitudes of clinicians to diagnostic overshadowing. Diagnostic overshadowing was a key theme within the published literature (Mental Health Foundation 2008; Woods et al. 2008) leading to late or missed diagnoses and poor prognoses in this patient group. It is evident therefore that these studies are significant not just in the need to breakdown stigma in clinicians which impacts on the treatment of the patient in the here and now, but also to break down the stigma which leads to delays in treatment, different treatment expectations, assumptions about mental illness and the ignoring of physical health conditions. Noblett, Lawrence and Smith (2015) call for increased research which aims to break down stigma and prejudice, and to motivate clinicians to reflect on their own attitudes to patients with mental illness and the impact on their clinical care.

These studies concern the attitudes of general healthcare clinicians, who are non-mental health specialists. Sadly, these attitudes are also present in mental health practitioners as well. Robson and Haddad (2012) outline the development of a measurement tool to assess mental health nurses' attitudes towards the physical healthcare of people with severe and enduring mental illness. Mental health nurses' attitudes to carrying out physical healthcare are impacted upon by lack of confidence but also in a lack of belief that the physical well-being of their patients can be improved, highlighting prejudicial views of the ability of people with mental illness to recover or to be physically well.

Disparities between clinician views and patient views can also arise. Lester, Tritter and Sorohan (2015) explored the perspectives of primary care health professionals to providing primary care to people with severe mental illness. The study highlights a disparity between the perceptions of primary care clinicians, that care for people with severe mental illness is too specialised for primary care and patients with serious mental illness, who viewed primary care as central to their healthcare. Patients valued a relationship with their GP more highly than the opportunity to be referred to a GP with specialist mental health knowledge. Key issues which arose were a perception that physical health complaints can be difficult to diagnose once a mental health diagnosis is known, and this was sometimes put down to communication difficulties between the GP and the patient.

A literature review, (Ross and Goldner 2009) exploring stigma, negative attitudes and discrimination towards mental illness within the nursing profession, found that nurses may be people who hold stigmatising views, but also may experience stigma as people who experience mental illness. The review also incorporates literature which concerns prejudice against psychiatric nursing and psychiatry as a speciality. The paper concludes that nurses are both the perpetrators and recipients of stigma relating to mental illness. Attitudes of fear and hostility to patients with mental illness were found to be relevant and to impact negatively on clinical care. Nurses working in mental health were also found to hold more pessimistic views about positive outcomes and recovery potential of patients than general nurses. The paper acknowledges that whilst it may be upsetting to discover that stigma and discrimination towards mental illness is significant, it locates this within the wider understanding of why all human beings might adopt defensive, discriminatory behaviour in relation to mental illness.

This section outlined some of the key literature which explores fear and stigma, both in society and in clinical practice, regarding mental illness which helps to understand the

barriers to providing PEOLC to patients with SMI, which relate to how clinical staff may feel about working with this patient group. The next section explores similar fears which underlie attitudes to working with dying patients.

2.4.3 Fear of Death and Dying

The fear of death and dying is deep-seated. Much has been written about the defence mechanisms employed by palliative and end of life clinicians to cope with the reality of working with people who are dying (Kocijan et al. 2007; Liechty 2000; Lindstrøm 1989; Wilson 2014; Yalom 2008; Zheng, Lee and Bloomer 2018). Many people shy away from talking about their own mortality. Understandings of death and dying are very culturally and religiously anchored. Some cultures and communities have a much more open, almost celebratory, relationship with the end of life in the same way most cultures celebrate the beginning of life and other significant life events or rites of passage (Littlewood 1992). In the UK, and much of western culture, attitudes towards death and dying are more sombre, still and quiet (Jalland 2017) and largely not discussed.

The overwhelming emotions which can arise when confronted with one's own mortality lead us to avoid thinking about our own death (Yalom 2008). The thought of coming towards the end of one's own life can provoke many responses, an existential crisis, avoidance, preoccupation leading to depression and anxiety (Nyatanga 2016). Working with dying patients can bring this anxiety to the forefront and whilst talking more about death and dying can be helpful for patients, it can also heighten death anxiety in clinical staff. Many healthcare staff want to heal, make well, and help patients' recovery. Palliative care staff are often assumed to be more comfortable with death and dying, but the deep-seated fears and anxieties are just as powerful, especially if proper supervision and reflective practice are not available to staff. However, PEOLC staff may have access to de-brief support and reflective space more than other healthcare staff. Payne, Dean and Kalus (1998) found that death anxiety was lower, but still present, in hospice nurses than in emergency department nurses, in part because they had access to colleagues to discuss their practice with and a greater culture of peer support. However, the dying patient presents a challenge to the healthcare professional in all settings. Nyatanga (2016) makes links between the impact of death anxiety and compassion fatigue, stating that inadequate support for staff can lead to negative experiences of death anxiety and in turn burnout. This can quickly turn to compassion fatigue and lead to avoidance and poor patient care.

The use of euphemisms to talk about death is part of the defence mechanisms used by clinicians, and wider society, to avoid death anxiety (Payne, Dean and Calus 1998; Peters et al. 2013). Terms such as ‘passed away’ and ‘slipped away’ are common even in PEOLC settings. Whilst it can be felt to be more sensitive, Nyatanga (2016) also argues this is part of avoiding death anxiety and can in fact exacerbate it and calls for a more open dialogue between clinicians and patients. It is important to note that this requires proper support to be in place for clinicians, but also for clinical staff to have access to training resources which support the development of skills to have these conversations. The fears and anxieties are deep-seated and the defence mechanisms used to protect individuals are well-established and cannot easily be overcome without this support.

Peters et al. (2013) carried out a literature review of fifteen studies which explore death anxiety in nursing staff. The review explores three key themes, the level of death anxiety amongst different groups of nurses, how death anxiety impacts upon attitudes to caring for the dying person and the nature of the death education which was required to support nurses in their work with dying patients. The review highlighted the lower levels of death anxiety in specialisms where dying patients are more prevalent such as hospice, oncology and renal services. Nurses who were older and those more experienced reported lower levels of death anxiety which might be expected. Interestingly, those with PEOLC training reported lower levels of death anxiety. It is important to note that mental health nurses were not included in the study, but as non-PEOLC trained nurses, would likely report higher levels of death anxiety. Peters et al. (2013) highlighted that death anxiety can be reduced by the provision of effective education about death and dying. Nurses who had negative attitudes also had a less positive attitude to caring for dying patients. This will be important to consider in the development of a resource which would aim to support mental health staff as well as PEOLC and general healthcare clinicians develop their confidence. In the same way that clinical staff may have negative attitudes to mental illness, they may also have similar attitudes to working with dying patients.

In addition, Hutchinson and Sherman (1992) carried out a study where student nurses participated in death education and found this had a positive impact on reducing death anxiety, which in turn helps to reduce compassion fatigue. Matsui and Braun (2010) and Zyga et al. (2011) also found the provision of death education to be beneficial to attitudes to caring for the dying person. The need for a mixed approach incorporating death

education and peer-led reflective support is evident and forms part of the considerations of the research design for this study.

2.5 Chapter Summary

This chapter has outlined the contextual background to the study. The key mental health and PEOLC policy and research has been presented. Despite a focus on improving the physical health of people with mental illnesses and aiming to achieve parity between mental and physical health services, the palliative end of life care needs of people with SMI and terminal conditions continue to be ignored at a policy and strategic level. Equally, despite a focus on improving understanding of, and access to, PEOLC for the general population, the needs of people with SMI continue to be excluded.

The previous research which was carried out by the researcher and which informs the aims and objectives of this thesis have been summarised. Background information which underpins fear and stigma in clinical practice and informs the view of people with SMI, as well as a summary of the fear surrounding death and dying have also been presented. If clinical staff experience fear of patients, they are more likely to avoid caring for the patient. The key aim of this research is to develop the concept for a resource which aims to improve care through building confidence and breaking down fear. This means developing a resource which addresses these fears, challenges stigma by humanising patients, helps staff to see the person behind the labels or diagnoses. The next chapter presents the findings from a literature review which considers methodological approaches and the use of co-creation in mental health and PEOLC.

Chapter 3 Literature Review

3.1 Introduction

This chapter presents the findings of the literature review which explores how co-creation methods have been used within 1) palliative and end of life care services and 2) mental health services to improve clinical practice. A literature review carried out by the researcher (Jerwood 2016) explored the experiences of people with SMI in end of life care. The results of this earlier literature review highlighted barriers in delivering care to this patient group and is summarised in Section 2.3 (Summary of Previous Research Projects).

The themes highlighted in this earlier review underpin the research design of this thesis. The review highlighted unanswered questions and gaps in the published evidence, some of which this thesis seeks to answer. However, a further literature review focusing on methodological approaches was also required.

Participatory methods, and co-creation more specifically, had been identified as a potential research approach, as outlined in Chapter 1 (Introduction). One of the gaps in the published literature was that the research which had been carried out concerning patients with SMI and terminal illnesses, and their end of life care needs, did not include the direct experiences of patients and carers. People with SMI are often marginalised in healthcare and in research. Therefore, an important methodological consideration for the researcher was how to ensure that patient and carer experiences were included in the research design in a meaningful way. Participatory research methods, particularly co-creation and co-design, offered a possible approach. There is a developing body of literature concerning how these approaches have been used in healthcare, but this review focuses specifically on how these methods have been used in PEOLC and mental health services.

3.1.1 Co-Creation Methods: Setting the scene

As discussed further in Chapter 4 (Methodology), co-creation methods have increasingly been used in healthcare settings to bring design principles to service improvement (Donetto, Tsianakas and Robert 2014; Palmer et al. 2018). In 2008, Sanders and Stappers (2008) outlined the changing role of users in the design process and the principles they describe can be seen within the increasing numbers of co-creation/design/production projects within healthcare both in the UK and internationally

(Robert et al. 2015). It is purported that co-creation methods place importance on equity between participants and are often used when seeking the views of marginalised or vulnerable groups (Boyd et al. 2012; Robert et al. 2015; The Kings Fund 2013). Arguably, whilst there is a growing body of published literature regarding the use of co-creation methods to improve healthcare (Palmer et al. 2018), the evidence base for effectiveness is still developing, particularly in relation to thinking about the consistency and quality of the application of co-creation (Borgstrom and Barclay 2017; Greenhalgh et al. 2016).

One approach which has been particularly popular within healthcare settings is Evidence-Based Co-Design (EBCD). The Kings Fund developed a freely-available toolkit to support healthcare staff and researchers in implementing EBCD to address a range of healthcare problems and improvements (The Kings Fund 2013). A fuller explanation of the EBCD Toolkit is included in Section 4.7.2. (Co-design Methods) Donetto, Tsianakas and Robert (2014) review the implementation of EBCD in quality improvement in healthcare noting the high reported rates of patient engagement and the intention to use EBCD in future projects.

The focus on patient involvement in health has led to a desire by healthcare staff, researchers and commissioners to find new ways of engaging patients and carers meaningfully in service improvement and innovation. This chapter will now outline the literature review questions, methodology and results and how these informed the research questions, aims and objectives for the research study.

3.2 Literature Review Methodology

A systematic approach to reviewing the literature was adopted to ensure all relevant papers were identified. Healthcare databases were searched between June and July 2017 using consistent search terms and subject headings.

3.2.1 Development of Literature Review Questions

The 'SPIDER' (Sample, Phenomena of Interest, Design, Evaluation, Research) tool (Cooke et al. 2012) was used to develop the research question (

Table 1). Tools such as 'PICO' (Population, Intervention, Comparison, Outcome) and PICOT' (Population, Intervention, Comparison, Outcome, Time) are used to enhance rigour in developing research questions (Aveyard 2014) but are more suited to quantitative research. 'SPIDER' was developed specifically for qualitative studies.

Table 1 SPIDER tool

	Search
Sample	a) Palliative/EOL services b) Mental health services
Phenomena of Interest	Use of co-creation/co-design/co-production methods to improve clinical practice
Design	Research studies – co-design, Evidence-Based Co-Design, co-creation, co-production, focus groups, interviews
Evaluation	Improving clinical practice, improving services, improving care, engagement with staff and patients/carers, involvement of staff and patients/carers
Research	Qualitative and Mixed methods

The following question was developed for this literature review:

> How have co-creation methods been used to improve clinical practice in a) palliative and end of life care services and b) mental health services?

3.2.2 The Search Strategy

Different terminology is used to describe all the elements of the research question. For example, mental health services may be described as community mental health services, psychiatric units, in-patient units and so on. End of life care services may be described as palliative care or working with terminally ill patients. Equally, co-design, co-creation and co-production are often used interchangeably or as umbrella terms, and specific forms of co-creation such as Evidence-Based Co-Design (EBCD) are also used. Therefore, the search strategy had to encompass all the possible combinations of terms used to ensure all relevant papers were identified (see Table 2).

Table 2 Search terms

Search 1	**Terms and Combinations**
Palliative and End of Life Care	"end of life service" or "end of life care" or "hospice" or "palliative care service" or "inpatient palliative care" or "community palliative care" or Palliat* or "termina*)
Co-creation Research Methods	"co-design" or "codesign" or "co-creat*" or "cocreat*" or "co-produc*" or "coprod*" "participat*" or "experience-based" or "EBCD"
Search 2	

Mental Health	"mental health" or "psychiatric" or "mental health services" or "psychiatric services" or "secondary mental health" or "community mental health services" or "inpatient psychiatric" or "inpatient mental health" Mental* or psychiatr*
Co-creation Research Methods	"co-design" or "codesign" or "co-creat*" or "cocreat*" or "co-produc*" or "coprod*" "participat*" or "experience-based" or "EBCD"

3.2.3 Databases searched

The databases used in the search included BNI, CINAHL, PsychInfo, Medline, and Academic Search Complete and were searched using the same search terms and subject headings where possible. The subject headings allowed individual conditions to be included under the search terms, rather than having to search by individual condition (i.e. psychosis could be included under the search term of mental health or mental illness by selecting it and using the search terms 'Mental*' and 'psychiatr*').

3.2.4 Inclusion and Exclusion Criteria

As the research study is focused on improving clinical practice, and co-creation methods are a relatively new methodology, a ten-year search period was used to capture recent research contributing to contemporary practice. Due to resource limitations of the study, only papers published in English were included. The initial search terms included user involvement and patient involvement, but this generated more than 150,000 papers so more specific terms which specifically capture co-creation approaches were used. The full inclusion criteria and exclusion criteria are as follows:

Included:

- Studies published in English
- Studies published since 2007
- Studies concerning co-design, co-creation and co-production
- Studies concerning improving clinical practice
- Studies concerning community and inpatient mental health services
- Studies concerning services in palliative care, end of life care, working with patients with life-limiting illnesses and long-term conditions (inpatient and community)
- Qualitative and Mixed methods Research studies

Excluded:

- Non-English language studies due to lack of translation resource
- Papers more than 10 years old
- Studies concerning non-co-creation methods
- Studies concerning generic staff and service user involvement (SUI), patient and public involvement (PPI) such as basic consultation
- Studies concerning other clinical areas and general use of co-creation in healthcare
- Non-research studies, commentaries, practice notes, discussion papers
- Quantitative studies

The aim of the review is to understand how co-creation methods, specifically, have been used in PEOLC settings and mental health settings to improve clinical practice. PPI and SUI within the NHS have been a priority for many years and there is a wealth of literature which concerns user involvement, however, user involvement includes a spectrum of activities ranging from feedback questionnaires through to full engagement in the design and creation of services. Therefore, papers which include generic involvement and participation methods were also excluded from the review.

3.2.5 Selection and Critical Appraisal Method

The database searches generated over 900 results across the two searches (see Figure 1). The first search concerning end of life care services generated 150+ results, and the second search concerning mental health services generated a much greater number (750+). This was expected as background research indicated that co-creation approaches have been more widely adopted in mental health services. Duplicate records were identified and removed, and records were manually screened for relevance and the majority (800+) were excluded by title.

A review of abstracts was then carried out on 9 papers concerning co-creation in PEOLC and 66 papers concerning co-creation in mental health settings. A final list of 29 papers (6 palliative care and 23 mental health) for full text review was generated. Twelve papers were excluded at full text review as they did not, after all, adopt a co-creation approach. 17 papers were selected for critical appraisal, 4 concerning PEOLC clinical settings and 13 concerning mental health settings.

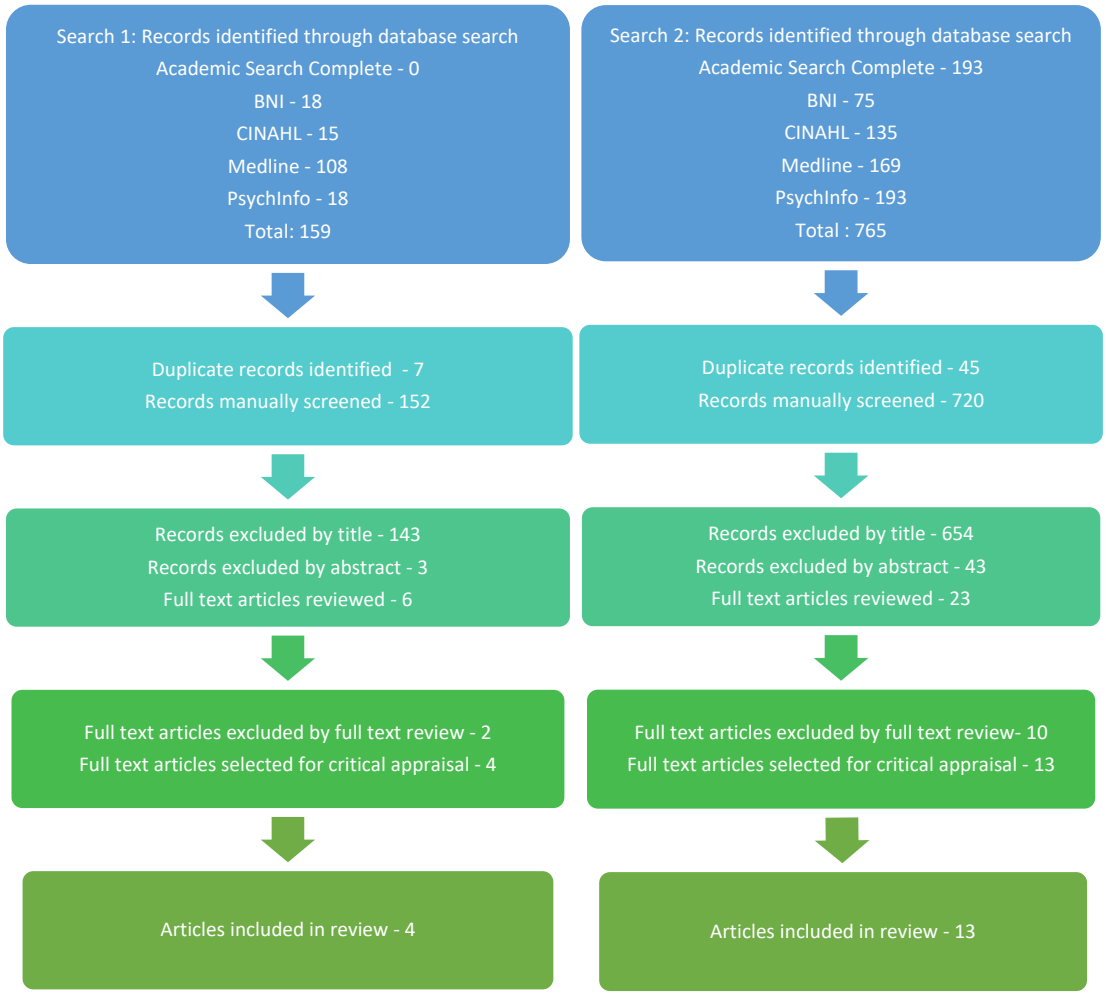


Figure 1 PRISMA diagram (Moher et al. 2009)

3.2.6 Critical Appraisal Method

Critical appraisal of the literature is important in establishing the quality of the research to be included in the review and supports the process of becoming familiar with the content. (Aveyard 2014). The Critical Appraisal Skills Programme (CASP) Qualitative Checklist (CASP 2017) was used to appraise the quality of identified studies. The CASP checklist offers a structured approach to the assessment of research studies for inclusion in reviews.

CASP was chosen because it offers ten structured questions and has been created specifically for assessing qualitative research papers. There are different tools available for the appraisal of qualitative studies. Garside's (2014) critical appraisal tool and Scharalder and Leonard's (2010) model of appraisal were also considered, but the CASP tool was chosen because it offered a concise but comprehensive framework for critical appraisal for this review.

Each study was assessed against the ten criteria (two screening questions and eight in-depth questions) and a decision about inclusion/exclusion was made based upon the quality of each research paper (see Appendix 4 for summary of Critical Appraisal).

3.2.6.1 Palliative and End of Life Care

The first search for literature concerning use of co-creation in PEOLC identified only six studies, two of which were excluded as they did not actually describe the use of co-creation methods in practice. One of the identified studies was a literature review concerning similar, but broader, topics by Borgstrom and Barclay (2017) which also identified a very small pool of literature (only 12 studies internationally). A published, peer-reviewed journal article, summarising this review has been included as one of the review papers because the original full report was not available to the reviewer at the time of writing. In their review, Borgstrom and Barclay also highlight that the relative recent adoption of co-creation methods in PEOLC may mean that usage may not be fully reflected within the literature yet and they call for greater dissemination of research findings using these methods. However, co-creation methods have been adopted for a range of purposes within PEOLC including improving experience of care pathways, developing resources for clinicians, gaining consensus on models of care and improving understanding of patients needs.

A small number of papers was expected as the use of co-creation in clinical settings in PEOLC is not yet well established, and may not yet be reflected across the published, peer-reviewed literature. Four papers were appraised, two clinically based research studies, one literature review summary paper and one study using expert professionals as participants aiming to develop consensus on a model of care.

3.2.6.2 Mental Health Care

Thirteen papers were appraised, two originating outside the United Kingdom (UK); one from Australia and one from Denmark; one joint UK and Turkish paper and ten UK studies. Two concerned the development of a clinical tool, five concerned service improvements, two concerned service design, three co-created research studies and one which concerned challenging attitudes of clinical staff using co-creation. The higher number of results in the search confirmed the wider application of co-creation methods within mental health settings, compared to PEOLC settings. Mental health services have a long history of patient involvement, which is not as advanced within PEOLC, so it was not surprising that there was a greater number of studies identified in this part of the

search. However, the vast majority of studies were excluded because they did not describe how co-creation methods had been implemented. Including the PEOLC papers, a total of seventeen papers were included in the final review.

3.3 Data Analysis and Synthesis

Following the appraisal of the literature, all 17 studies were included in the review, and a thematic analysis and synthesis of the data carried out. The mental health papers and the PEOLC papers were brought together and analysed as one body of literature, rather than two separate reviews, because the aim of the review was to explore how these methods had been used in both settings and with both patient groups and to draw out similarities and differences in terms of methodological implementation. A thematic analysis was used as the researcher was aiming to understand the range of ways co-creation has been adopted within both areas of clinical practice. There were no pre-agreed codes or themes applied, instead all potentially relevant themes were identified. Other data analysis methods such as meta-ethnography (Noblit and Hare 1998) and meta-analysis (Glass 1976) were considered. Meta-ethnography is an approach which involves the interpretation of qualitative findings, rather than summarising the data (Aveyard 2014). Meta-analysis involves the combining of results of studies to provide new data not found in individual studies to generate new findings. As the scope of this review was to understand the themes within the literature, rather than to generate new findings a thematic analysis was used.

Each study was read by the researcher. Each paper was summarised (see Table 3 and Table 4) and then an open approach was used to code the studies. Open coding was used as there is little known about the subject of the review. The coding process was carried out manually by the researcher. A manual process was chosen, rather than using software such as NVivo, as the researcher was reviewing the use of the methods, rather than the topic, theme or findings of the papers. There was concern that using software would not identify all useful data. An initial list of codes was generated. The initial codes were discussed with members of the supervisory team and refined. All papers were re-read and the coded data was clustered into key themes and sub-themes. The themes were discussed with the supervisory team to add rigour to the coding process and subsequently refined. Two overarching themes, each with three sub-themes, were identified in and are presented in Section 3.4 (Results and Discussion of Emergent Themes).

Table 3 Summary of papers reviewed - Search 1

No.	Article	Summary
1.	Blackwell, R. W. et al. (2017) 'Using Experience-Based Co-Design with Older Patients, their Families and Staff to Improve Palliative Care Experiences in the Emergency Department: A Reflective Critique on the Process and Outcomes'.	A UK paper exploring the use of EBCD to improve palliative care experiences of older people and their families in ED's. Use of EBCD led to: Higher levels of engagement of patients, families and staff Tangible products and changes to improve care Amplification of the patient experience (vulnerable group) First time EBCD used to engage patients, carers and staff to improve palliative care in the ED Paper is a critique of the EBCD methods and a sharing of the data about the PC needs of OP in the ED setting Some flexibility of approach is needed, and indeed desirable, but use of EBCD is both possible, and beneficial to vulnerable groups Flexibility of EBCD is its greatest strength
2.	Borgstrom, E. and Barclay, S. (2017) 'Experience-Based Design, Co-Design and Experience-Based Co-Design in Palliative and End-of-Life Care'.	Literature review of use of EBCD, co-design and experience-based design in PC and EOLC. 12 studies internationally, varying adoptions of CD approaches – inconsistent involvement of patients and carers Summary of full report. Links principles of palliative care to principles of EBCD – person-centred approaches Acknowledges increase of use of co-design in healthcare, but limited use so far in EOLC/PC Acknowledges positive impact of co-design approaches but highlights greater need for dissemination, evaluation and publication of studies using these models
3.	Davies, N. et al. (2016) 'A Co-Design Process Developing Heuristics for Practitioners Providing End of Life Care for People with Dementia'	UK-based, dementia focused study using co-design to develop content of heuristics to improve clinical staff decision-making regarding EOL interventions in dementia patients Paper focuses more on findings of the research than the methodology used
4.	Iliffe, S., et al. (2013) 'Modelling the Landscape of Palliative Care for People with Dementia: A European Mixed Methods Study'	An internationally focussed paper using co-design methods to create a consensus for a model of palliative care for people with dementia Alternative approach to methods like Delphi? Is it co-design if no patients/carers represented directly? Or is this an appropriate adaptation of a model to achieve the aim of the study?

Table 4 Summary of papers reviewed - Search 2

No.	Article	Summary
5.	Chambers, M. et al. (2016) 'Service User Involvement in the coproduction of a mental health nursing metric: The Therapeutic Engagement Questionnaire'.	UK- based study using co-production with service users of mental health services; aims to develop a tool to measure therapeutic engagement between SU's and RMN's SUI long history within MH, co-production less so and still emerging Study adopts principles of SU as expert, key stakeholder in service development TEQ developed was much more fit for purpose due to involvement and participation of SUs and clinical staff, despite not achieving full equity of participation in the co-production process
6.	Cooper, K. Gillmore, C and Hogg, L. (2016) 'Experience-based co-design in an adult psychological therapies service'	UK-based study using EBCD to improve services in adult psychological therapies investigating challenges which arise when using EBCD in a MH setting EBCD was well received by SUs, staff and stakeholders, modified approach
7.	Cranwell, K. Polacsek, M. and McCann, T. (2016) 'Improving mental health service users, with medical co-morbidity transition between tertiary medical hospital and primary care service: A qualitative Study'.	Australian study using EBCD to improve care pathways between tertiary medical services and primary care for MH SUs Acknowledges the physical ill-health needs of people with mental ill health EBCD as a useful approach, identifies themes from the data, concludes a whole -service approach is needed to improve care
8.	Freeman, L. R. et al. (2016) 'Working towards co-production in rehabilitation and recovery services'	UK-based case study, reflective paper, focusing on implementing co-production within rehab and recovery MH services Reflective, co-produced paper located within recovery narrative Using co-production to produce a co-production strategy Moving beyond SUI/participation to embedding co-production principles in the organisational culture
9.	Gillard, S. et al. (2012) 'Producing different analytical narratives, coproducing integrated analytical narrative: a qualitative study of UK detained mental health patient experience involving service user researchers'.	UK-based study exploring how service user involvement in research impacts of research findings. How co-analysis of data produces new knowledge, which can improve services. Little previous research beyond enhanced validity/rigour of analysis Co-production of the research, not co-production methods of collecting data
10.	Gillard, S. (2012) 'Patient and Public Involvement in the Coproduction of Knowledge: Reflection on the analysis of qualitative data in a mental health study'.	UK-based study exploring impact of involvement on the research process and findings Knowledge co-production as a tool for evaluating impact of PPI on health research

11.	Larkin, M Boden, Z. V. R. & Newton, E. (2015) 'On the brink of genuinely collaborative care: Experience-based co-design in mental health'.	UK-based study which explores turning the findings of three qualitative studies into service improvements using EBCD in early hospitalisation in early episode of psychosis Adapted form of EBCD used, adapted for MH service, explores implications of using with vulnerable patient group, challenges and successes identified and implications for future practice
12.	Lwembe, S et al. (2016) 'Co-productions an approach to developing stakeholder partnerships to reduce mental health inequalities: an evaluation of a pilot service'.	UK-based study using co-production to engage marginalised group (BAME) in psychological therapies service (IAPT) Aims to evaluate participant's experience of co-produced services Positive findings, small study, suggests co-production of services helps overcome barriers to access to services
13.	Meddings, S. et al. (2014) 'Co-delivered and co-produced: creating a recovery college in partnership'.	UK-based study – co-producing a recovery college Case study and reflection on the process, using action research Positive impact on co-production on a service-user orientated provision such as recovery college Challenges explored
14.	Pinfold, V. et al. (2015) 'Co-production in mental health research: reflections from the People Study'.	UK-based study reflecting on the experience of co-producing research; co-produced paper
15.	Springham, N. and Robert, G. (2015) 'experience-based Co-Design reduces formal complaints on an acute mental health ward'.	UK-based study using EBCD in mental health setting (adapted) to address the number of formal complaints on an acute in-patient assessment ward EBCD used to address problems relating to staff attitudes and communication, mis-aligned priorities between staff and patients Useful study in relation to choice of methodology and inclusion of narrative and visual methods Co-design used to address observation of problem from clinical setting
16.	Tee, S. and Ozcetin, Y. (2016) 'Promoting positive perceptions and person-centred care toward people with mental health problems using co-design with nursing students'.	UK and Turkey study looking at co-design of education to challenge perceptions of mental illness amongst nursing students Poorly described co-design process Example of using co-design to challenge attitudes rather than service development/improvement Co-design used in relation to a marginalised group Useful paper for background and methodology
17.	Terp, M. et al. (2016) 'A room for design: Through participatory design young adults with schizophrenia become strong collaborators'.	Danish study using participatory design to develop an app with young adults with schizophrenia; aims to create a more participatory clinical practice in RMN's Co-design process described with vulnerable patient group Co-design is beneficial for working with vulnerable patient groups – impact is felt beyond the impact on the end product of the co-design process; impact on culture of organisations and esteem of patient participants

3.4 Results and Discussion of Emergent Themes

Two overarching themes, each with three sub-themes, were identified in the thematic analysis of the literature.

1. Opportunities of Using Co-creation in PEOLC and Mental Health Settings
    - Stakeholder Inclusion and Equity
    - Flexibility of Co-Creation methods
    - Improved Engagement and Impact
2. Challenges of Using of Co-Creation in PEOLC and Mental Health Services
    - Inconsistency of Methodological Approach
    - Ethical Issues
    - Clinical Challenges

Themes are presented below in Table 5 and Table 6. The number of studies the theme arose within is included in brackets and the study number is identified in the final column.

3.4.1 Theme 1 – Opportunities of Using Co-Creation in PEOLC and Mental Health settings

As discussed in Chapter 4 (Methodology), the epistemological and ontological origins of co-creation methods lie in participatory action research (PAR) and place emphasis on the participation and engagement with the patient or service user (Blackwell et al. 2017). Co-creation methods involve service users and other stakeholders in the creation and design of services and interventions. In both clinical settings, many opportunities and benefits of adopting co-creation approaches, in their broadest sense, were highlighted. These have been clustered into three main sub-themes following analysis of the data. There were also challenges and gaps in the evidence based identified and these are presented in Section 3.4.2 (Theme 2 – Challenges of Using C-creation in PEOLC and Mental Health Services).

Table 5 Overarching themes and sub-themes: Opportunities

Overarching Theme	*Sub-Theme*	*Coded data items*	*Occurrence of Data Item Search 1 EOLC*	*Occurrence of Data Item Search 2 MH*	*Study Number*
Opportunities of Using Co-creation in PEOLC and Mental Health Services	Sub-Theme 1 Stakeholder Inclusion and Equity	Improved understanding	(4)	(6)	1,2,3,4,6,7,11,12,13,15
		Amplification of patient/carer voice	(4)	(13)	1,2,3,4,5,6,7,8,9,10,11,12,13, 14,15,16,17
	1a Inclusion of Patients, Carers and the Family	Similarity of values/shared ethos	(1)	(6)	2,6,9,13,14,16,17
		Co-created services more appealing to patients	(1)	(1)	2,12
		Patient-focused/equity of patient	(1)	(6)	4,5,7,13,15,16,17
		Co-production moves SU engagement beyond involvement/consultation		(3)	5,6,11
		Patient seen as asset		(8)	5,6,8,9,10,11,14,17
		Use of co-creation with marginalised group	(2)	(6)	1,2,7,8,11,12,14,17
		Involvement in research process as well as design of intervention		(4)	6,8,9,14
		Capacity building of participants		(6)	9,10,12,13,14,17
	1b Inclusion of Clinicians	Amplification of staff voice	(4)	(5)	1,2,3,4, 6,8,14,15,16
	Sub-Theme 2 Flexibility of the Co-creation methods	Flexibility of Co-creation	(1)	(3)	1, 6, 15, 17
		Value of flexibility	(2)	(6)	1,2, 7, 9, 10, 11, 15, 17
		Need for flexibility	(2)	(2)	1,2, 6, 8
	Sub-Theme 3 Improved Engagement and Impact	Informed change to practice	(4)	(1)	1, 2, 3, 4, 14
		Improved relationships	(3)	(2)	1, 2, 3, 11, 13
		Improved engagement	(3)	(3)	2, 3, 4, 12, 15, 17
		Improved impact	(3)	(3)	1, 2, 4, 5, 9, 10
		Power of visual methods	(2)	(5)	1 ,2, 6, 7, 11, 15, 17
		Stakeholder focused	(2)	(1)	1, 3, 5,
		Improved quality of end product	(1)	(4)	3, 5, 12, 13, 15
		Enhanced rigour of process	(1)		3,
		Consensus gaining	(1)	(3)	4, 11, 14, 15
		Creating the environment for co-creation		(3)	8, 11, 17
		Stigma challenged		(4)	11, 12, 15, 16

3.4.1.1 Stakeholder Inclusion and Equity

A key area where co-creation methods were found to be beneficial is in the inclusion and equity of stakeholders with researchers. Co-creation methods are often adopted when improving care for a vulnerable or marginalised group (Blackwell et al. 2017; Davies et al. 2016) and both dying patients and people with long-term mental illness are often marginalised and excluded from research, service improvement and involvement, as well as in society. Despite a focus on service user involvement in mental health particularly, services providers and researchers still struggle to involve service users, patients and carers in a meaningful way. The desire to amplify the voice of the patient, and their families and carers, with a view to improving care, was evident in all the included studies. This desire appears to be the key motivating factor in the adoption of co-creation methods in the clinical setting, in all its forms, for service improvement, co-created research studies and co-creation of education resources. Cranwell, Polacsek and McCann (2016) carried out a study in a mental health setting which aimed to improve the patient experience of transition between services using Experience-Based Co-Design (EBCD). The researchers brought together groups of clinicians and patients at different stages of the project including a focus group where all stakeholders attended together. The results of the project included patients and carers being able to share their experiences of clinicians' prejudicial attitudes and the impact of this on their care, and carers being able to share their experience of being under-valued by clinical staff. Clinicians were able to hear first-hand accounts which challenged their practice but in a collaborative environment which was focused on improvement and moving forward. Other studies echoed these themes. All studies referred to a benefit of co-creation being the amplification of the patient and staff experience. When co-creation methods were adopted, patients, carers and clinical staff reported feeling more engaged and included in service developments and research and staff, particularly, reported that their preconceptions of the possibility of change had been challenged in a positive way.

Blackwell et al. (2017) describe the changes made to services following an EBCD project to improve palliative care in the emergency department. Staff priorities were identified, patient and family priorities were identified and then matched and a solution which addressed both concerns was identified. Staff had previously expressed the opinion that palliative care in this setting could not be improved but reflected afterwards on the impact on the patient experience of what seemed to be small changes (Blackwell et al. 2017). Patients reported feeling more listened to and staff felt they understood patient experience better than they had before involvement in the co-creation process.

One challenge in traditional approaches to service user involvement is avoiding tokenistic consultation or involvement. Seven studies (Chambers et al. 2017; Cooper, Gillmore and Hogg 2016; Cranwell, Polacsek and McCann 2016; Meddings et al. 2014; Springham and Robert 2015; Tee and Üzar Özçetin 2016; Terp et al. 2016) identified that co-creation methods were found to be useful in overcoming this by placing patients and carers on an equal level with other participants and researchers. Gillard et al. (2012a) explore the impact of service user researchers and academic researchers working together in the research process. In particular, analysing the impact of service users carrying out interviews and their different interpretations of research data and how these can be integrated to create co-produced knowledge. This approach places the service user on a much more equal footing than traditional service user consultation or involvement activities.

In contrast to the PEOLC literature, seven mental health studies (Chambers et al. 2017; Cooper, Gillmore and Hogg 2016; Freeman et al. 2016; Gillard et al. 2012a; Larkin, Boden and Newton 2015; Pinfold et al. 2015; Terp et al. 2016) move beyond discussions of equity of involvement of patients to highlighting the patient as an asset, emphasising the unique skills of patient participants. Pinfold et al. (2015) reflect upon the value of co-produced service development research, both to the participants and to the quality of the outcomes of the research and service development. By valuing the service user participant as an asset and as an expert in the research process, rather than a subject of it, Pinfold argues that both the quality and relevance of the research is improved and also that the research process is democratised (Pinfold et al. 2015). Terp et al. (2016) argue that in contrast to the common perception that people with mental health problems are inherently vulnerable, they are in fact both able and keen to participate in co-creation processes, if the importance of creating a space of possibility for co-creation is held in mind. In a similar way to Springham and Robert's (2015) adaptation of EBCD to consider the past traumatic experiences of service users, Terp et al. (2016) advocate a focus on creating the space, mindfully, and on the preparation of the co-design environment. This connects to a further sub-theme which focuses on the benefits to the service user or patient participant of taking part in a co-creation process, beyond the involvement in the service improvement in question. Studies refer to improvements in self-esteem (Terp et al. 2016), gaining skills and knowledge (Lwembe et al. 2017; Meddings et al. 2014) and developing as researchers (Gillard et al. 2012a; Gillard et al. 2012b; Pinfold et al. 2015).

Whilst inclusion of patients, carers and families was a key theme in the literature, another significant theme emerged which related to the inclusion of clinicians and other staff stakeholders in co-creation projects. In the same way that co-creation can amplify patient views and experiences, it can also amplify staff experiences. Clinical staff, particularly those at the front line of service delivery can often be excluded from service redevelopment or redesign. Pressures on frontline services mean it is often managers who are able to attend meetings, forums or workshops where consultation about service development is carried out. In the same way patients can feel 'done to', there is also a possibility of staff feeling a similar way. Co-creation approaches encourage the inclusion of all key stakeholders, not just patients. This includes frontline clinical staff who are often the implementers of changes in clinical practice or pilot initiatives. Cooper, Gillmore and Hogg (2016) used EBCD for service improvement in an adult psychotherapies service. The study describes the EBCD process and highlights how staff were included and draws comparisons between staff and service user views and opinions in its analysis. The study notes that sometimes participation in co-design can be intimidating to staff, but that there is great value in including clinician views. In the same way as involving service users has been found to lead to greater efficacy of the end product, involving clinical staff can lead to greater 'buy-in' to improvements or change. Springham and Robert (2015) describe how EBCD was used to reduce complaints on an acute mental health ward. The process of capturing service user experiences on film, and bringing all stakeholders together to view the films, led to greater understanding of staff to service user's experiences. This process also allowed staff to express themselves and for their voices to be heard and incorporated into service improvements. In a study to develop heuristics to aid practitioners, Davies et al. (2016) illustrate how involving the staff, as well as patients, in the development of a resource which is going to be used by staff leads to a more effective end product. The development of the heuristics relied on an understanding of clinical thinking which the clinician participants were able to provide. Blackwell et al. (2017) highlight the benefit to implementation of involving both patients and staff in co-creation. Involving patients and carers can lead to more patient-friendly improvements, but if they are difficult to implement, then they often fail. Involving staff, and those staff who will be involved in implementation or delivery, not senior managers, leads to more practical and patient-centred improvements and enhances buy-in from clinicians in the process.

3.4.1.2 Flexibility of Co-Creation Methods

The flexibility of co-creation methods was repeatedly cited in the literature. Flexibility was highlighted as both desirable and possible. It was highlighted as **desirable** within a co-

creation process due to competing resource pressures, staff availability and fluctuating well-being of patients and **possible** within the different models of co-creation adopted by the research teams. Blackwell et al. (2017) refer to alterations made to the EBCD schedule to accommodate an overseas study visit and changes to staffing within departments. The fluctuating well-being of patients, especially when working with vulnerable groups such as those with dementia (Blackwell et al. 2017; Davies et al. 2016), and the limited availability of carers and families (due to caring responsibilities) also mean flexibility is necessary and desirable. Co-creation methods were found to be able to accommodate flexibility and change, and this mitigated against a sub-theme in Theme 2 Clinical Challenges - Resource Intensiveness, which arose as a possible limitation of using co-creation methods in thirteen of the seventeen selected studies (see Table 6 Overarching themes and sub-themes: Challenges).

In mental health services, the benefits of co-creation approaches in relation to flexibility were similar to PEOLC. The flexibility of the approach, even where a specific and detailed toolkit exists, such as in EBCD is desirable and often used to address a range of factors such as resource limitations, time, funding but also in response to patient and staff need. Springham and Robert (2015) highlight the need for adaptation of EBCD to ensure positive outcomes for the service improvement do not come at the expense of patients or become exploitative, referring to the use of patient story in the EBCD model. In acknowledgement of the traumatic experiences participants may have had on the in-patient unit, the researchers provided additional preparatory meetings with participants prior to them attending the co-design workshops. This was to provide space to process the difficult feelings which may have arisen previously and which may set patients apart from other stakeholders including clinicians and researchers.

Larkin, Boden and Newton (2015) adapted EBCD methodology to work with vulnerable groups by using film to give amplification to the patient voice and adapted the Kings Fund toolkit to achieve the specific project aims. Terp et al.'s study (2016) highlights the need to avoid applying a rigid process to the co-creation project and highlights the importance of allowing the process to evolve from within the group. The need to respond to staff concerns about confidentiality and power imbalances, and the ability to be flexible within the co-creation process is helpfully highlighted by Cooper, Gillmore and Hogg (2016). In some instances, staff may not feel comfortable expressing views on film, especially if there is not organisation-wide support for the co-creation process. Cooper, Gillmore and Hogg (2016) chose not to use staff films but still allowed staff to participate and highlight

that this adaptation can lead to inequities between stakeholders which need to be considered when setting co-creation projects up.

Most papers reviewed highlight that co-creation methods offer a *desirable* and *possible* flexibility. The need for flexibility when working with dying patients and people with long-term mental ill health was explored as well as the ways in which co-creation approaches can be applied or developed flexibly. This is particularly important when working with vulnerable patient groups such as those with mental illnesses and terminal conditions, patients in services where deprivation of liberty and mental capacity issues may be more prevalent, and where there may be tensions between patient and staff viewpoints.

3.4.1.3 Improved Engagement and Impact

The third key opportunity offered by co-creation methods concerns engagement and impact. This theme highlights how co-creation leads to improved engagement of the stakeholders involved. In fact, those who feel traditionally 'done to', or the subjects of change, research, or innovation, become the stakeholders in the process. The improved engagement of staff, patients and carers was evident in the results of the review. In addition, the quality of the 'end product' of the co-creation process, whether it be research, service innovation or re-design, was identified as a key benefit. The improvements to engagement and impact are highlighted across all the papers reviewed. Davies et al. (2016) highlight how the process of developing heuristics to aid decision-making in clinical staff was enhanced by the engagement of patients and families in the design process. In addition, the heuristics would be used by nursing staff to help decision-making in end of life care. The involvement and engagement of those staff in developing the heuristics, rather than having a clinical tool imposed, led to more useful tools being developed and added greater rigour to the process (Davies et al. 2016). Illiffe et al. (2013) describe the use of co-design to gain consensus, as an alternative to traditional methods such as Delphi studies. This is echoed by Larkin, Boden and Newton (2015) who used EBCD to look at improvements in experience of hospitalisation for young adults with psychosis. The need to gain consensus, whilst not the explicit aim of co-creation, is implicit in the process. Synthesizing patient, carer, staff and organisational expectations and experiences of the issue under consideration is a central element of the co-creation process and it is argued in the literature (Illiffe et al. 2013; Larkin, Boden and Newton 2015; Pinfold et al. 2015; Springham and Robert 2015) that shared understanding of the issues, leading to consensus on improvement approaches, leads to better engagement with the process and the outcome.

The improved understanding between stakeholders which arises when co-creation methods are adopted is highlighted extensively in the review by Borgstrom and Barclay (2017). Across the literature, there is little to suggest there is any disadvantage of using co-design methods in terms of engagement and impact. All papers discuss the improvement in understanding between staff of patients' needs, and between staff groups, of the process of developing improvement interventions.

Visual methods were found to be inherent in the improved engagement and impact of the co-creation process. Use of film, of art materials, graphics and prototyping techniques in co-design for visualising and modelling patient journeys in co-production and co-creation approaches are well-documented in the wider literature (Aitken and Shackleton 2014; Pearce et al. 2018; Sanders and Stappers 2014; Terp et al. 2016; Ward et al. 2015). Visual methods are used in two ways: in how data is collected and debate is facilitated; and in the end product of the process.

The most common use of visual methods in this body of literature was the use of film, which is also a central part of the EBCD process. Blackwell et al. (2017) highlight how the use of film within the EBCD process allowed staff to hear patient views which they previously struggled to hear or accept. This process is echoed in the EBCD study carried out by Springham and Robert (2015). Individual staff members' attitudes were noticeably changed when viewing the filmed patient experience. This led to staff suggesting a second film be made, capturing staff experiences. Seeing and experiencing the power of the films of service users led staff to suggest this second film. In some studies, clinical staff expressed concerns about expressing their views and being filmed (Cooper, Gillmore and Hogg et al. 2016). This led to the co-design process being adapted. However, this created issues of inequity between staff and patient participants and the researchers highlight the importance of both staff and patient participants being filmed. This is discussed further in Section 3.4.2.2 (Ethical Issues). It is interesting to note that service users received greater input at the preparation stage, in acknowledgement of their vulnerable position, but it may be that staff participants also require similar input to feel comfortable being filmed. Borgstrom and Barclay (2017) highlight the importance of film in highlighting the 'touchpoints' in the patient's journey and film is used as an emotive way to highlight areas which need addressing or exploring in the co-design process. This is echoed by Larkin, Boden and Newton (2015) who used film to remind participants of the key priorities they previously identified therefore using film as a form of evidence to keep participants focused.

Larkin, Boden and Newton's (2015) study explores the tension between the impact of filming participants, be they staff or patients, and the need to protect confidentiality and anonymity. Films created as part of EBCD or other co-design projects should be stored in the same way as any other research data. If films are to be used for different purposes after the co-design process is finished, or used to highlight the findings of the process, there is a need to edit, renew consent and involve the participants to ensure this does not become exposing. This is further explored in Section 3.4.2.2 (Ethical Issues). The content of the film created by Springham and Robert (2015) in their study to improve rates of complaints on an acute inpatient unit became part of a staff training programme following completion of the study. It became a valuable resource which contributed to the longevity of the co-design process. This is important as one of the challenges explored in Section 3.4.2.3 (Clinical Challenges) relates to sustainability issues. However, it is important when creating a safe space for the use of any visual method, that participants understand how the images and objects, including films, will be used and the confidentiality surrounding the research process (Borgstrom and Barclay 2017; Cranwell, Polacsek and McCann 2016; Larkin, Boden and Newton 2015; Springham and Robert 2015).

The use of other visual methods in the co-design process was limited in the papers reviewed. Sanders and Stappers (2008) advocate use of a range of creative methods to facilitate discussion and to capture discussion and findings. This was not reflected in the papers reviewed, which highlights again the over-reliance on EBCD which is discussed in Section 3.4.2.1 (Inconsistency of Methodological Approach). EBCD advocates use of film, which is sometimes not practical or desirable, and is often the part which is adapted or altered in clinical settings. However, there was little discussion of the other methods which can be used to capture experiences, views and stories. An exception is the study by Terp et al. (2016), which used graphic facilitation to capture the discussion and data in the co-design process. Graphic facilitation is an approach which uses images and words to create a shared language. The graphic recorder, usually an artist, captures the content of the workshop or discussion onto large charts or images which the group can see. This approach was adopted by the researchers in response to the limitations of the participant group (people with recently diagnosed schizophrenia). Metaphor and symbols were used to capture ideas and experiences. Terp et al. (2016) suggest that use of visual methods stimulates creativity and interaction which helps participants think of themselves as designers instead of patients.

With vulnerable groups, participation can fluctuate, but the flexibility and use of visual methods within co-creation methodology was found to help achieve engagement even when participants are too poorly to take part at times. Davies et al. (2016) adopted a co-design approach to developing heuristics (visual prompts) to improve clinical decision-making in end of life care for patients with dementia. Due to disease progression, some patients were not directly involved, but families and carers were part of the co-design process. Given that the 'end product' of the co-design was a clinical resource for staff, it could have been that only staff were involved in the process. However, the co-design process is based upon engagement of all stakeholders and the involvement of families and carers led to inclusion of topics which may have otherwise been excluded. Blackwell et al. (2017) undertook a process of EBCD to improve experiences of palliative care in Emergency Departments (ED). A significant finding was the capture and sharing of priorities of staff and patients and families and the differences between the two groups. The sharing of these priorities between the two groups of stakeholders, which forms part of the EBCD process, allowed staff to better understand what matters to patients and their families when receiving palliative care in the ED.

3.4.2 Theme 2 – Challenges of Using of Co-Creation in PEOLC and Mental Health Services

Several key challenges of adopting co-creation methods were highlighted in the review. Many of these challenges relate to variability of how methods were implemented and the different levels of participation in the process by different stakeholders. In addition, because the focus of most of the papers is the end product of the co-design process, rather than the methodology, it was sometimes difficult to fully analyse the consistency between different approaches.

Table 6 Overarching themes and sub-themes: Challenges

Overarching Theme	*Sub-Theme*	*Coded data items*	*Occurrence of Data Item Search 1 EOLC*	*Occurrence of Data Item Search 2 MH*	*Study Number*
Challenges of Using of Co-creation in PEOLC and Mental Health Services	Sub-Theme 4 Inconsistency of Methodological Approach	Elevation of EBCD as a tool within healthcare – over other forms of co-creation	(2)	(3)	1, 2, 6, 11, 15
		Inconsistent application of CD approaches (link to elevation of EBCD)	(1)	(3)	2, 7, 8, 11
		Inconsistent leadership of co-creation process	(1)	(4)	4, 5, 7, 11, 14
		Lack of consistency of analysis of data/generalisability of findings		(1)	7
		Need for more evaluation/challenge in evaluating	(1)	(2)	2, 7, 11
		Need for further research	(1)	(4)	2, 6, 7, 11, 12
		Need for greater dissemination of research findings	(1)		2
		Methods should be more widely adopted	(1)		2
	Sub-Theme 5 Ethical Issues	Ethical concerns when using of visual methods:	(1)		
		- with patients		(2)	1, 6, 11
		- with staff		(1)	6
		Ethical issues of working with vulnerable groups of patients	(2)	(2)	1, 2, 11, 16
		Importance of consideration of ethical principles	(1)		2
		Power dynamics between staff and patients		(1)	15
	Sub-Theme 6 Clinical Challenges	Resource Intensive	(2)	(11)	1 ,3 ,5, 6, 8, 9, 10, 11, 13, 14, 15, 16, 17
		Challenge of the clinical setting/patient group	(2)	(4)	1,2,6, 8, 11,17
		Recruitment balance/equity of participation	(1)	(7)	2, 5, 8, 9, 10, 11, 13, 14
		Change of organisational culture		(4)	7, 8, 11, 15
		Sustainability	(2)	(6)	1,2,5, 6, 8, 11, 15, 17
		Importance of communication		(4)	11, 13, 15, 17
		Fear of speaking out – staff and patients		(2)	6, 11
		Participants need training in co-creation methods		(2)	6, 8

3.4.2.1 Inconsistency of Methodological Approach

The first key challenge of adopting co-creation methods is that it is an emerging research methodology. The evidence-base is developing; however, the review highlighted a need for more guidance and structure to be developed for *how* to implement these methods in both clinical settings to maximise the opportunities of flexibility and address the challenges of inconsistency. The inconsistency of how co-creation methods are used within end of life care and mental health settings is highlighted in five of the reviewed studies (Blackwell et al. 2017; Borgstrom and Barclay 2017; Freeman et al. 2016; Cranwell, Polacsek and McCann 2016 and Larkin, Boden and Newton 2015).

The published evidence base is relatively recent across both clinical settings. Interestingly, all the papers reviewed concerning PEOLC settings were published within the last four years, and three in the last 18 months (Blackwell et al. 2017, Borgstrom and Barclay 2017, Davies et al. 2016). Arguably, there is a longer history of using co-creation in mental health services but, again, all but three papers (Gillard et al. 2012a, Gillard et al. 2010, Meddings et al. 2014) have been published in the last three years. Borgstrom and Barclay (2017) highlight the lack of published papers and call for more research to be carried out using these methods and wider dissemination of co-creation research. Cooper, Gillmore and Hogg et al. (2016) echo this calling for more research to be carried out on implementing EBCD in mental health settings and Cranwell, Polacsek and McCann (2016) state that further research on the impact of the resources developed through co-design needs to be carried out. Future research carried out should focus on the *implementation* of co-creation methods as well as the *efficacy* of the improvements and innovations developed using co-creation.

Flexibility was cited as a key opportunity and benefit within co-creation, particularly in clinical settings where patients may be more vulnerable. However, the flexibility of the methods also brings some challenges. The downside of flexibility, which was cited as both *necessary* and *desirable* when working with vulnerable or marginalised groups, is that sometimes this increases the inconsistency in how co-creation and co-design methods are implemented. Even when EBCD was used, which has an implementation toolkit available (The Kings Fund 2013) to guide implementation, there was a variety of approaches to the process. This is not necessarily always negative as discussed before, however, it makes comparing the efficacy of the approaches more challenging in the review.

Furthermore, Borgstrom and Barclay (2017) note that variations in who is involved and whether all stakeholders are engaged equally exist in many of the studies within their review. Across the papers reviewed here, the involvement of the patient varies, sometimes appropriately as in Davies et al. (2016) where it would be unethical or impossible to involve the patient directly due to disease progression; or for convenience as in Illiffe et al. (2013) where voluntary sector organisations were used to represent patients and families. The varied understanding of co-creation methods, the absence of a standardisation of approach and the terms co-creation, co-production and co-design being used interchangeably, leads to variations in how co-creation methods are implemented. The difficulty with such inconsistency is that it can lead to essential elements of what makes co-creation desirable being omitted for ease or convenience.

In addition, the degree to which equity between service user and patient participants was achieved in the studies was also variable, but the adoption of co-creation methods brought the importance of equity to the attention of the research teams and was critically reflected upon in several studies. Springham and Robert (2015) draw attention to the complexities of achieving equity when working with mental health service users who may have been, or who are currently, detained under sections of the mental health act. This contrasts with PEOLC services who do not have this inequity to overcome. The acknowledgement of traumatic experiences of accessing or being detained in mental health services is important to acknowledge and may impact upon the achievement of equity between service users and clinician co-creation participants.

Furthermore, there is also a lack of focus on describing or analysing the methodology in the research papers published which focus largely on the end product of the co-creation process, not the process of co-creation itself (Borgstrom and Barclay 2017; Cranwell, Polacsek and McCann 2016; Larkin, Boden and Newton 2015). Further research may include development of guidelines for implementing co-creation approaches, possibly incorporating a minimum standard to set co-creation methods apart from generic service user involvement approaches.

Aside from the Kings Fund toolkit for EBCD, there were no other standardised models or toolkits used by researchers using other forms of co-creation or co-design in the reviewed papers. The review found that this links to the inconsistent application and elevation of EBCD as co-creation approach. EBCD is an approach widely adopted in healthcare settings, with projects in 59 settings across six countries cited (Donetto, Tsianakas and Robert 2014). The Kings Fund developed a free, online toolkit (The Kings

Fund 2013) which provides a structured approach to implementing EBCD. This appears to have led to an elevation or focus on EBCD as a methodological approach which is evident in the review by Borgstrom and Barclay (2017) and the number of studies (Blackwell et al. 2017, Cooper, Gillmore and Hogg 2016; Cranwell, Polacsek and McCann 2016; Larkin, Boden and Newton 2015; Springham and Robert 2015) using EBCD or an adapted form of it, across this review as a whole.

As these methods are relatively new in healthcare, those seeking to implement them may look for structured approaches and guides. None of the papers using EBCD discussed why EBCD had been adopted in relation to other forms of co-creation. The use of EBCD was justified in relation to its wider adoption in healthcare service improvement and research, rather than in comparison to other co-creation approaches which are less defined. Because many co-design and co-creation approaches are not laid down as a 'how to' format, it could be argued that researchers have leant towards EBCD when in fact other methods, such as creative co-design, value co-creation, technology co-design or participatory action research could be more appropriate (Greenhalgh et al. 2016).

Four papers (Chambers et al. 2016; Cranwell, Polacsek and McCann, 2016; Larkin, Boden and Newton 2015; Pinfold et al. 2015) highlight the inconsistencies in leadership of co-creation projects. Larkin, Boden and Newton (2015) highlight the importance of high-level organisational leadership in relation to the implementation of identified improvements following the co-design process. There are variations in the literature on where leadership of co-creation sits, some studies are solely researcher-led, whereas some are clinician-led. For example, the studies by Pinfold et al. (2015) and Larkin, Boden and Newton (2015) originate from a desire to explore how the method can inform the research theme, in contrast to the studies by Tee and Özçetin (2016) and Davies et al. (2016), where a clinical issue was identified and co-creation methods were used to address it. None of the studies were led by service users or patients and there still seems to be some distance between current practice and patient led co-creation. This may relate to funding and resource issues. Some studies appeared to be motivated by a desire to implement and evaluate a co-creation approach, whereas some were more focused on a particular issue which needed to be addressed, and co-creation was used to address it. All rely on funding and resources being available, which may impact on how patient-led they can be. The varied approach to data analysis, particularly the analysis of co-creation workshop data, which is often visual is also noted (Borgstrom and

Barclay 2017). This is reflected in the other studies by a lack of inclusion of discussions concerning how the co-creation data was analysed beyond brief reference to thematic analysis.

3.4.2.2 Ethical Issues

Ethical issues were highlighted as a challenge within the body of literature. The perception of vulnerability of the patient and the use of co-creation was particularly emphasised in three papers (Blackwell et al. 2017; Cooper, Gillmore and Hogg 2016; Larkin, Boden and Newton 2015). The use of co-creation is often linked to the desire to understand the experiences of marginalised or vulnerable patient groups (Donetto, Tsianakas and Robert 2014). Blackwell et al. (2017) also explore the fluctuating ability of patients to remain involved in a co-design process, and Davies et al. (2016) highlight the need to engage with families and carers in co-design when patients may be too unwell to participate but stressed their care needs need to be understood. The flexibility of co-design approaches was cited as a mitigating factor in involving vulnerable patient groups. Sometimes the researcher's fear of exposing vulnerable patients to service improvement leads to a lack of meaningful involvement. Indeed, this is part of the history of paternalistic healthcare which co-creation seeks to challenge (Sanders and Stappers 2008).

In contrast to the end of life literature, several of the papers in the mental health literature (Larkin, Boden and Newton 2015; Pinfold et al. 2015; Springham and Robert 2015) highlighted the power dynamics between staff and patients in some mental health settings, particularly when patients are or have been detained under sections of the Mental Health Act (2007). It is important to consider the power dynamics between patients and staff when designing co-creation interventions and the preparatory work which may been needed to overcome ethical issues relating to power imbalances and to build trust. Staff may also require preparation to feel confident in participating, particularly in having their views captured on film (Cooper, Gillmore and Hogg 2016). Clarity about the boundaries of confidentiality and the use of film, patient and staff experiences and the data collected in the co-creation process is as important as in any other research process (Blackwell et al. 2017; Borgstrom and Barclay 2017; Cooper, Gillmore and Hogg 2016; Larkin, Boden and Newton 2015)

The ethical issues of using visual methods such as film and using 'real' patient and staff stories are explored in several papers (Borgstrom and Barclay 2017; Blackwell et al. 2017; Cooper, Gillmore and Hogg 2016; Davies et al. 2016; Larkin, Boden and Newton

2015). Issues of consent and consideration of the longevity of films are considered but the risk is mitigated by the evidence of improved impact on clinical staff understanding of patients' needs. Blackwell et al. (2017) explore the differences between staff and patient priorities and uses direct quotes from staff to highlight how hearing, via film, a patient talking about their priorities in care, especially, the incidental, day to day things such as a smile, being offered a drink, and being reassured, are so important to a positive experience of care (Blackwell et al. 2017). This difference in priorities is also explored in a mental health setting in Springham and Robert's (2015) EBCD study. The difference in priorities of staff and patients is highlighted through the creation of films and then the sharing of the films between staff and patients. The creation of films incorporating both staff and patient experiences required all participants to feel safe in the process, planning and preparation. Organisational support and culture are all referred to as important factors in this process, supporting an ethical approach to implementing EBCD.

Larkin, Boden and Newton (2015) adapted the use of film and carefully edited interview footage to simultaneously raise the issues and highlight priority areas for focus whilst bearing the sensitivity of the content in mind. Participants were showed the films before they were used. The sensitivities in the relationship between patients and clinical staff in a mental health service were also considered. The review identified a clear need to consider how to overcome these ethical challenges when designing co-creation research studies and projects to ensure that the opportunities are fully realised.

3.4.2.3 Clinical Challenges

All the studies in the review, from both clinical settings, included issues which can be summarised as the clinical challenges of implementing co-creation methods. A prominent theme which arose in both clinical settings were the resource requirements. Twelve papers (Blackwell et al. 2017; Chambers et al. 2017; Cooper, Gillmore and Hogg 2016; Davies et al. 2016; Freeman et al. 2016; Gillard et al. 2012a; Gillard et al. 2012b; Larkin, Boden and Newton 2015; Meddings et al. 2014; Pinfold et al. 2015; Springham and Robert 2015; Tee and Özçetin 2016) refer to the different resources required, and the challenges encountered by the researchers. Resource issues included clinical staff having time to participate in the co-creation process, creating time and space to prepare for the co-creation workshops and resources required to ensure patient participants felt able to take part on an equal level. Studies using EBCD (Blackwell et al. 2017; Cooper, Gillmore and Hogg 2016; Cranwell, Polacsek and McCann 2016; Larkin, Boden and Newton 2015; Springham and Robert 2015) particularly commented on the time, and

expertise, required to edit the films used. Larkin, Boden and Newton (2015) refer to the need to edit films to ensure content still functions to trigger discussion whilst not leaving patient participants exposed or vulnerable. Cooper, Gillmore and Hogg (2016) refer to the reluctance of staff to take part in filming, for fear of expressing their views on camera. Better preparation, like that provided to patient participants (Springham and Robert 2015) may have helped staff to feel more comfortable participating. The planning and preparation can seem to be a large investment of time and resource upfront, and particularly in organisations where co-production or service user involvement are not culturally embedded, this can be a challenge. Gillard (2012b) explores co-creating research and provides a useful account of the preparation required to ensure service user involvement is not tokenistic and creating a research team where patient and academic researchers work as equals.

Three papers (Cooper, Gillmore and Hogg 2016; Freeman et al. 2016; Larkin, Boden and Newton 2015) referred to the challenges of implementing co-creation in a mental health setting. Mental health settings are different to PEOLC settings in that many service users have had long histories of negative engagement with organisations, may be detained and may also be impaired by their mental illness. This can make implementation in a mental health setting challenging, but as Springham and Robert (2015) and Terp et al. (2016) demonstrate, co-creation can be very effectively implemented with people with severe mental ill health in acute in-patient settings with the correct planning and support. A parallel between mental health and PEOLC settings is the fluctuating well-being of patient participants. Both the dying patient and people with SMI can experience fluctuating health which can impact upon participation.

Both staff and patients in mental health settings expressed fear of speaking out, especially in sharing negative experiences (Cooper, Gillmore and Hogg 2016; Larkin, Boden and Newton 2015). This linked to the challenge of creating equity between staff and patient participants, especially when working on secure units or with detained patients (Larkin, Boden and Newton 2015; Pinfold et al. 2015; Springham and Robert 2015).

There were more challenges identified in implementing co-creation approaches in mental health settings, however, there are some challenges in implementation in PEOLC settings specifically. Some patients become too unwell to participate during the co-creation process. Blackwell et al. (2017) recruited family members and carers into the study in addition to patients and they were able to continue to participate if the patient

participant became too unwell. Borgstrom and Barclay (Borgstrom and Barclay 2017) identify a persistent perception of the palliative patient as vulnerable or too unwell to take part (this is echoed in views of mentally unwell patients also). However, the paper cites the more general (and shared with mental health) challenges identified across both clinical settings as more significant challenges; gaining management buy-in for the approach (exacerbated by a lack of published research into using co-creation methods in PEOLC), resource issues, staff availability and sustainability.

Nearly half the papers (Blackwell et al. 2017; Borgstrom and Barclay 2017; Chambers, M. et al. 2017; Cooper, Gillmore and Hogg 2016; Freeman et al. 2016; Larkin, Boden and Newton 2015; Springham and Robert 2015; Terp et al. 2016) discussed the sustainability of co-creation approaches. Retaining the expertise of staff in services where staff turnover is high (Springham and Robert 2015), cascading the approach and embedding it within the organisational culture (Borgstrom and Barclay 2017; Cooper, Gillmore and Hogg 2016), sustaining support from leaders in the organisation (Chambers et al. 2016; Larkin, Boden and Newton 2015; Springham and Robert 2015) were all highlighted as issues. Where co-creation had been implemented as part of a research study, sustainability was an increased concern (Cooper, Gillmore and Hogg 2016; Gillard et al. 2012b) rather than where it had been adopted to address an improvement arising from within the clinical setting.

3.5 Conclusions

This literature review examined how co-creation methods have been used within a) palliative and end of life care and b) mental health services to improve clinical practice. The term co-creation has been used throughout the review but encompasses all co-design, co-production, experience-based co-design and co-creation methods adopted in the papers reviewed.

Co-creation methods, and particularly EBCD, are increasingly being adopted in healthcare settings, including mental health services and PEOLC. Co-creation methods are being used to fulfil a range of functions; to improve care pathways, to gain consensus on models of care and to develop clinical resources. Co-creation methods are often adopted to work with vulnerable or marginalised groups, to better understand patient and family experiences, or to ensure that the products and interventions developed meet the needs of patients and clinical staff. Although there is a focus on patient and carer engagement within the literature, there is also a theme concerning the engagement with

clinical staff. Co-creation methods offer an effective way to engage with clinical staff in the overall improvement of care.

The most important benefit of using co-creation methods is that of the increased engagement in the process of service improvement and the amplification of the patient and carer experiences and views. This research study aims to address three key gaps in the published evidence. The first relates to understanding the experiences and views of people with co-morbid mental illness and terminal conditions. The second to the need to move beyond describing the barriers to providing PEOLC to this patient group and towards developing solutions. The third is a concern with the development of the methodology, and particularly to the quality of data analysis approaches. When planned properly, co-creation methods offer the opportunity for participants to work together as equals and there was no evidence in the review to suggest that these methods cannot be used with dying patients or with people with mental ill health.

There were some differences in the mental health literature to the PEOLC literature. There is a far greater focus in the papers which concern mental health settings on ethical considerations, confidentiality and vulnerability of the patient group. In addition, because service user involvement has a much longer history than in end of life care, the principles of co-creation have been adopted much more widely in mental health settings than in end of life and palliative care settings so the body of literature was greater.

The review found that co-creation methods have been used in a variety of ways in both clinical settings including improving care pathways, developing new products and resources, in research studies and in improving training of clinicians. Both clinical settings work with patients who have been marginalised in different ways and which are sometimes also marginalised in the wider structure of the NHS and health environment. In addition, both settings have staff and patients whose views are sometimes misunderstood and where stigma affects perceptions of both patients and the care provided.

The review identified that co-creation methods can be useful tools when trying to gain the views and experiences of marginalised or vulnerable groups. The flexibility of the different forms of co-creation methods enhanced their usefulness with these groups. Where patients may be too ill to take part sometimes, study design was able to be adapted to include carer's views instead, or to allow for fluctuating participation. Working with patients who have fluctuating health and mental well-being is sometimes unpredictable and hard to plan. Key to the success and to maximising the benefits of co-

creation methods is planning and taking time to adapt to the clinical setting, without diluting the method. Co-creation methods, when planned thoroughly, offer patients who are vulnerable, impaired or unwell opportunities to participate in different stages and in different ways. For example, a participant may be well enough to participate in a filmed or recorded interview but may not be well enough to attend a workshop or co-creation event. Or they may be unable to participate in a traditional focus group verbal discussion but may be able to contribute to visual and creative data collection which does not require verbal participation. The review concluded that there was no reason not to use co-creation approaches with people with SMI or terminal conditions, but that research design must take vulnerability and patient well-being into account.

There were challenges and considerations identified in the results which would need to be addressed in the research design. One of the key challenges identified was the resource intensiveness of co-creation methods. This was particularly the case when EBCD was used. It linked to another finding which was the sustainability of the methods. Sometimes co-creation is used to improve services and change organisational culture and it was highlighted that this can be a challenge if the support for the approach is not obtained from the higher levels in the organisation. The over reliance on EBCD as a method, which appears related to the availability of a toolkit, was linked to the resource intensiveness and the inconsistency of application of co-creation methods. The approach had been adapted within several studies to reduce resource burden and to increase participation. Whilst this flexibility is important and highlighted as a benefit, it also contributes to a lack of consistency in how the methods are adopted, which makes evaluating quality and efficacy more challenging.

One of the difficulties within the review was that the papers tended to focus on the end product of the process, and the impact on participants. Whilst this was helpful to analyse and certainly is a great advantage of co-creation, it led to a lack of focus on the research design and research methods in the body of literature. One of the conclusions of the review, and which was highlighted in several papers, is that there needs to be a continued focus on developing the evidence-base for co-creation methods, particularly the consistency of application, developing guidance for researchers and clinical staff and focusing on how data collected in co-creation-based research is analysed.

The use of visual and creative methods was a strong theme throughout the review. It was found to be a positive aspect of co-creation methods, allowing participants to understand each other’s experiences and views from different perspectives. It was also

found to be a helpful way for participants to think differently about a problem and potential solution. There were some tensions in capturing participants views and experiences on film; this was the case for both patients and staff. The preparation which patients received to mitigate against this may also be useful for staff and increase willingness to be filmed. The power of the filmed content in provoking a change in attitudes and better understanding was found to be a great advantage but requires careful consideration depending on the setting and dynamic between participants. Only one paper (Terp et al. 2016) explored the use of different creative methods, beyond film, in contrast to the wider literature about co-design and co-creation methods. This seems to be a missed opportunity and the Terp et al. (2016) paper is useful in the justification of why a range of creative methods of data collection is desirable.

The synthesis of the findings from the literature review emphasised the value and opportunities that co-creation methods can offer patients who are vulnerable, impaired or unwell to participate in research, in different stages and in different ways. Allowing all participants to understand each other's experiences and views from different perspectives was a key factor in selecting this method and directly influenced the development of the research questions, aims and objectives of the study.

3.6 Research Questions, Aims and Objectives of the Study

The findings of the literature review and previous research findings led to the development of the research questions:

- What are the views and experiences of patients with severe mental illness, and informal care network members, of care and treatment when diagnosed with a terminal condition?
- How does co-design support the creation of a clinical education/information resource? What are the key features of such a resource?
- Can the use of visual and creative methods enhance the impact of a clinical education/information resource?

The aims of this study were to:

- Gain an understanding of the views and experiences of patients with severe mental illness, and informal care network members, on their palliative and end of life care needs and their experiences of receiving care.
- Apply this understanding to the development of a co-designed educational/information resource to improve approaches to clinical practice.
- To contribute to the development of co-design methodologies and the analysis of co-design data.

The objectives of this study were to:

- Explore the views and experiences of patients with severe mental illness and life-limiting conditions on:
    - their end of life care needs (emotional, physical, social and psychological)
    - their experiences of receiving palliative and end of life care
    - the barriers to accessing palliative and end of life care
    - what skills and knowledge clinical staff may need when supporting access to, and delivering end of life care, to people with severe mental illness and how care can be improved
- Explore the views and experiences of carers on the palliative and end of life care needs of patients with severe mental illness, barriers to accessing timely and appropriate care, and the knowledge and skills clinical staff need and how care could be improved

- Co-design the concept and initial content of an educational resource to improve clinical practice with small groups of patients, informal care network members, and clinical staff (from palliative, end of life and mental health services)
- Explore the use of visual methods that may enhance the impact of the resource
- Provide a rich description of the approach taken to the analysis of visual data

3.7 Chapter Summary

This chapter has presented the findings of a systematized literature review which explored how PEOLC and mental health services have used co-creation methods. The results identified key issues for consideration when adopting co-creation methods into research design in studies involving people with SMI and terminally ill patients. Both the opportunities and the challenges were identified.

The contextual background, previous research and literature reviews all contributed to the development of the research questions, aims and objectives. A need to move beyond describing the barriers to providing PEOLC to people with SMI and to develop the concept and content of an improvement resource was identified. A key priority was to explore the views and experiences of patients and those who care for them and involve them in the research design, as well as making the best use of the opportunities which co-creation offer.

The research questions, aims and objectives are presented at the end of the chapter. The next chapter presents the methodology and research methods adopted in the study, including the rationale for the chosen research design, data collection and analysis methods.

Chapter 4 Methodology

4.1 Introduction

This chapter describes the methodology used within the research study. A summary of how the literature reviews, earlier research and the researcher's background contributed to the development of the research questions is included at the beginning of the chapter. The chapter goes on to explore the research paradigm and philosophical position of the thesis. Ethical considerations and approvals are then outlined. The chapter goes on to discuss the research design, methods for data collection and analysis.

An earlier literature review (Jerwood 2016), summarised in Section 2.3 (Summary of Previous Research), highlighted the need for further research which develops interventions to improve care and which moves away from just describing the barriers to delivering PEOLC to people with severe mental illness. It also highlighted an absence of the direct experience of patients and carers in the published research. A previous study (Jerwood et al. 2018) explored the views of clinical staff in PEOLC and mental health services and found that a key barrier to the delivery of effective PEOLC for people with SMI was a fundamental lack of confidence in clinical staff when working outside their own specialism. Clinicians identified a need for a resource which built confidence, and clinical skills, through addressing the underlying fears and stigma surrounding death, dying and mental illness as well as providing information and guidance. Factors such as accessibility, lack of time and funding to attend training courses, the need to better understand patient and carer experience and the need to amplify the patient's voice were highlighted as factors to consider when developing any educational or information resource to improve care. The potential of online, web-based resources was highlighted in the findings of the study and is further explored in this chapter and the subsequent co-design process. Co-creation methods have increasingly been used in healthcare when working with marginalised groups. Co-design has been used particularly when designing web-based and educational tools. The literature review for this study focused on methodological questions exploring the use of co-creation approaches in PEOLC and mental health services.

4.2 Research Paradigm and Philosophical Considerations

4.2.1 The Participatory Paradigm

Each researcher brings a different approach to answering a research question based on their background, their philosophical beliefs about the nature of reality and about how knowledge is created, and their own worldview. This thesis is informed by both constructionist/constructivist and participatory philosophical positions. A constructivist viewpoint does not assume a single ontological view of a reality but rather that there are multiple realities and understandings of truth or experience; in other words, that lived experiences and social relationships affect understanding of reality. Guba and Lincoln (1994) state that constructivist realities are ‘multiple, intangible mental constructions, socially and experientially based’ (Guba and Lincoln 1994: 110). The epistemological position, the relationship between the knower and what can be known, is transactional and subjective, informing the findings and knowledge generated during the process of inquiry.

A participatory philosophical position shares some of the constructionist standpoint of multiple realities, socially or interactively constructed meanings and an interactive approach to the collection of data. Heron and Reason (1997) build upon Guba and Lincoln’s (1994) understanding of the constructionist view and develop an additional participatory paradigm which offers an alternative philosophical standpoint which provides a different framework of understanding. Chambers (2008) refers to the participatory paradigm as a ‘new paradigm’, 'a coherent and mutually supportive pattern of concepts, values, methods and action amenable to wide application' (Chambers 2008:1266).

Heron and Reason’s participatory paradigm (1997) has underpinned their use of participatory action research and co-operative inquiry. It provides a framework which describes the nature of reality as interactive, existing between subject and object. This contrasts with a traditional positivist viewpoint where the researcher seeks ‘truth’ as the active participant from the passive subject of the research. Heron and Reason (1997) state that the participatory paradigm offers an ‘extended epistemology’ and outline four forms of knowing; practical, propositional, presentational and experiential. The participatory paradigm advocates collaboration, co-operation and interactive approaches to data collection. A mix of collaboration (promoting connection between participants) and autonomy (promoting achievement and self-determination) is defined as optimal

'human flourishing'. This is interesting and important to consider when working with marginalised participants. Heron and Reason (1997) state, as a further development of Guba and Lincoln's (1994) model, that the *axiology* of knowledge, in other words what is intrinsically worthwhile knowledge, centres on a combination of *collaboration* and *autonomy*. The principles of collaboration, shared participation and empowerment are key underpinning principles in any co-creation or co-design study. The importance of giving voice to marginalised participants and of equalising the relationship between participants is central to this study. It is interesting to highlight that a theme from the study of clinicians' views (Jerwood et al. 2018) was that a lack of collaboration between professionals and organisations, and lack of professional autonomy experienced by clinicians, were barriers to delivering effective care.

In developing the design for this study, it was important to consider how patient and carer voices could be amplified and how participants' experiences and beliefs could be understood and inform the design of a resource. Traditional approaches would have involved 'experts', researchers and/or designers, developing a resource and then testing it or asking for feedback from patients (Foot et al. 2014). Holliday, Magee and Walker-Clarke (2015) present the difference between traditional, linear consultation approaches and iterative, co-design approaches visually (see Figures 2 and 3).

It was as important to consider how the *patient* voice could be heard as it was to consider how the *clinician* voice could be heard. Some of the underlying barriers in delivering good care relate to imbalances in power between patients and clinicians and between frontline clinicians and managers. Additional barriers lie in the deeper held fears and stigmatised views of mental illness, death and dying prevalent amongst healthcare staff and in society more widely.

A methodological approach which promoted equity, participation and collaboration was required. Heron and Reason (1997) place collaborative inquiry at the centre of the participatory research paradigm 'in which all involved engage together in democratic dialogue as co-researchers and co-subjects' (Heron and Reason 1997). A participatory approach challenges the traditional approach which involves carrying out research about or on participants, and instead encourages researchers to carry out research with participants (Bergold and Thomas 2012).

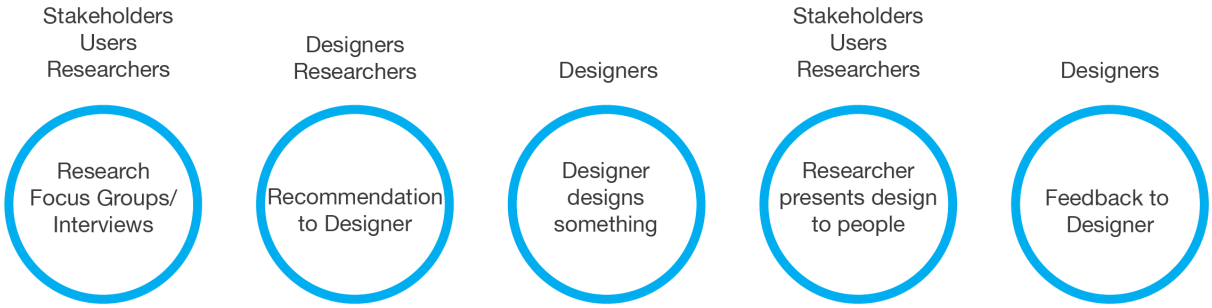


Figure 2 Traditional consultation approach

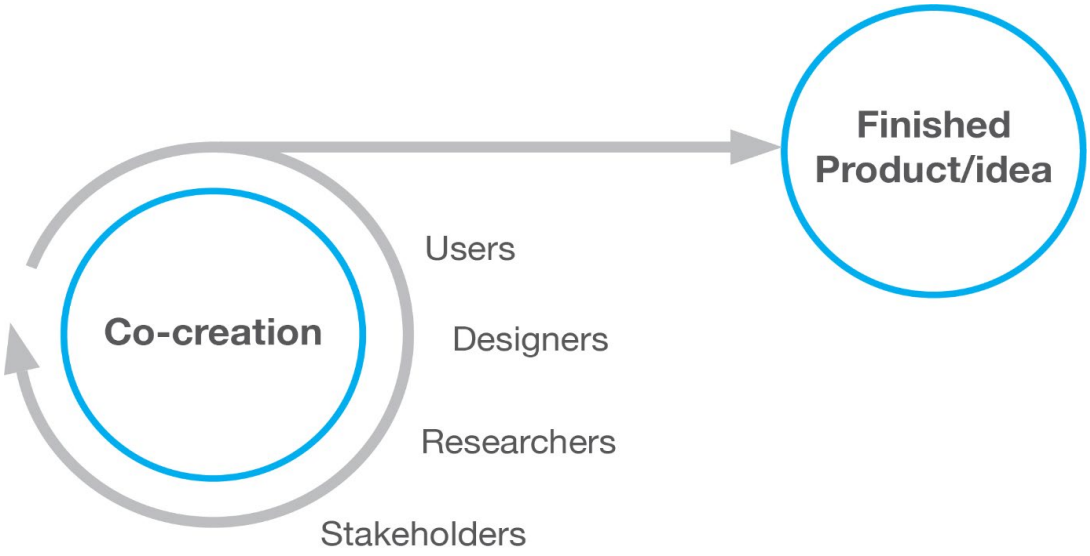


Figure 3 Co-design approach

4.2.2 Working with marginalised participants

The research study was informed by a belief that patients, carers *and* clinical staff often hold the answers to clinical problems but do not have the power to influence change. People with mental illnesses are often disempowered, disadvantaged and have been under-represented in previous research studies and within the development of strategy, policy and practice (Mental Health Foundation 2008; Shalev et al. 2017). Clinical staff participants are also often the subjects of research studies or the implementers or subjects of service re-designs or organisational change rather than being equal participants in the development or design of these processes. There are similarities between the experiences of clinical staff and patients in terms of lack of equity within the research process; the research approach underpinning this study aims to address this. Key to the research design was a principle of equity and involvement. Building on the NHS focus on Patient and Public Involvement (PPI) and Service User Involvement (SUI) (Foot et al. 2014) the researcher was keen to use participatory methods to ensure that

the patient voice was central to the development of the resource, as well as to ensure that the end users of the resource, predominantly clinical staff, but potentially patients and carers themselves, were equal participants in the development and design of the resource.

4.3 Research Approach and Design

A qualitative approach was used to explore participants' views and experiences of the research questions and to address the stated aims and objectives. A qualitative approach is useful where little is known about a topic, or where views and experiences of participants are being sought, or where different perspectives may be held by participants (Bricki and Green 2007). The study's research questions include exploring and understanding the perspectives of patients and qualitative methods allowed the patient experience to be understood and explored.

Participatory research has two objectives: firstly to generate knowledge and action directly useful to a group of people, and secondly to empower those people through constructing and using that knowledge (Heron and Reason 1997). The design of this study aimed to adopt both objectives with a view to improving care through amplifying the patient voice and empowering participants to develop solutions through a process of co-design.

This research study had two parts. Part One was a series of semi-structured interviews with patients and carers. The views of clinicians have been reported in an earlier study (Jerwood et al. 2018). The absence of interviews with people with SMI and terminal conditions, and their carers, was highlighted as a significant gap in the literature within the UK and internationally. The analysis of the interview transcripts and the themes identified were used to inform the design of the second part of the study, along with the themes from the previous clinician study and literature reviews. How the interview findings informed the workshop stages is further discussed in Chapter 7 (Discussion - Section 7.2.6).

Part Two was a series of workshops which aimed to bring together patients, carers, PEOLC clinical staff and mental health staff (in their broadest sense) to co-design the content and format of a clinical resource which aims to improve care. The study design is captured in Figure 4. The rationale for the choice of research methods is discussed in Section 4.7 (Methods).

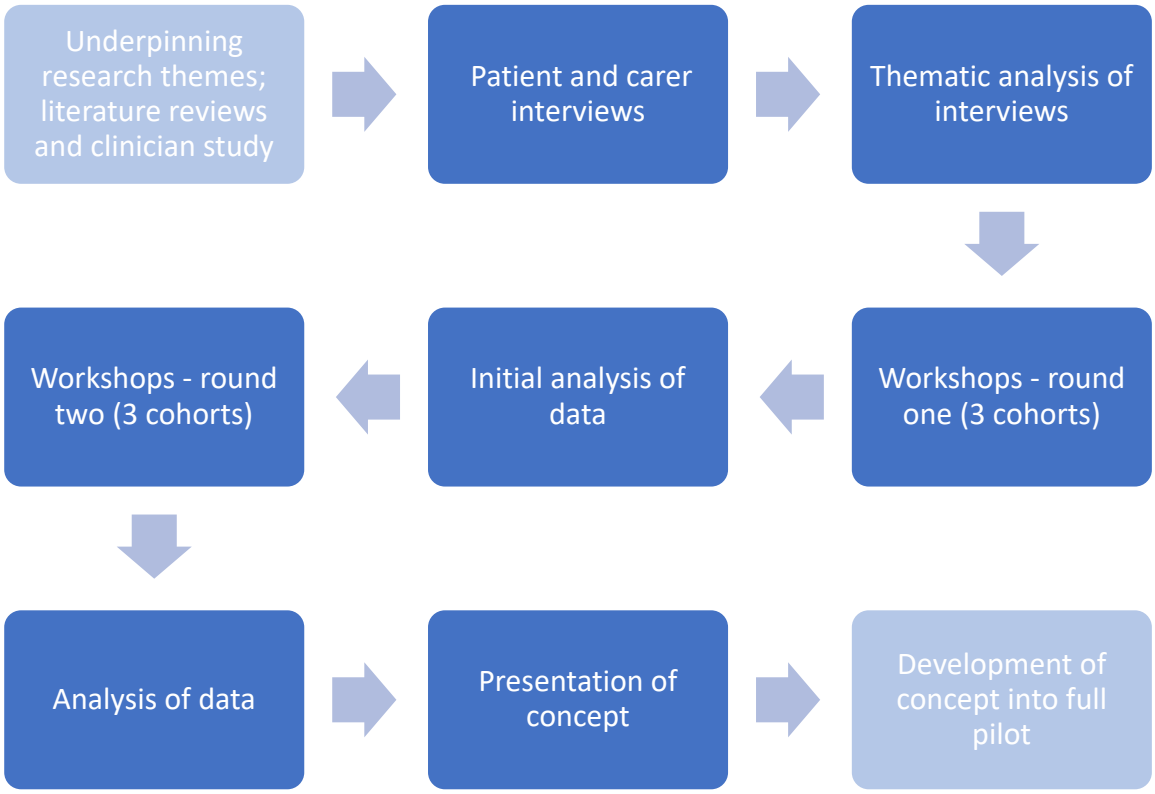


Figure 4 Study Design diagram

The first and last boxes fall outside the remit of the thesis. The underpinning research was carried out as part of a Health Education England (HEE)/National Institute of Health Research (NIHR) Masters by Clinical Research study the year before the PhD study commenced. The final box refers to the steps that will be taken following the submission of the thesis as part of the dissemination of the findings, recommendations for practice and the development of the concept into a full pilot for further and post-doctoral research.

4.4 Quality in qualitative research: a framework for addressing the quality of the research

The importance of demonstrating quality in qualitative research is essential and has been discussed by many (Bochner 2000; Cresswell 2007; Flick 2018; Guba and Lincoln 2005; Miles, Huberman and Saldana 2014; Seale 1999; Spencer et al. 2003; Tracy 2010). The debate has largely centred on defending the robustness and rigour of qualitative research methods compared to quantitative approaches and is ongoing (Greenhalgh et al. 2016).

There is a need to move beyond defending the research tradition to quantitative or positivist researchers. Qualitative research assumes the existence of multiple realities as opposed to a single truth or reality. Therefore methods of assessing quality of qualitative research need to embrace this principle. In addition, qualitative research encompasses many different research methods and methodologies so defining a single quality framework or set of criteria is problematic. Qualitative research, particularly exploratory, co-created research, does not seek to find a universal, generalisable answer to a problem; it seeks rather to explore and co-create solutions in collaboration.

Multiple frameworks and checklists have been developed over many years to address the problem of how to measure the quality of qualitative research. In considering how to introduce a framework to assess quality in this thesis several existing models were considered. Firstly, Guba and Lincoln (1985) proposed a five-point criterion list to establish the rigour of qualitative research. This includes trustworthiness, credibility, dependability, transferability and confirmability, later adding an additional criterion of authenticity. Guba and Lincoln's criteria are critiqued by Seale (1999) who notes that the development of criteria to assess quality is at odds with a philosophical position which assumes multiple realities (Seale, 1999: 468).

Spencer et al. (2003) reviewed existing frameworks to develop a single quality framework for assessing qualitative evaluation and research which was adopted by the Cabinet Office for evaluating qualitative research evidence. The framework offers four central principles which underpin the 18 appraisal questions. The four principles advise that research should be contributory, defensible in design, rigorous in conduct and credible in claim. The 18 appraisal questions cover the key processes involved in qualitative inquiry: assessment of findings, research design, sampling, data collection, analysis and reporting, as well as general features of research conduct such as consideration of reflexivity and neutrality, ethics and auditability (Spencer et al. 2003). Similarly, Tong et al. (2007) reviewed 76 items from 22 pre-existing checklists to develop a 32-item checklist for assessing quality of qualitative research (COREQ). The COREQ framework offers 32 questions clustered into three domains: research team and reflexivity, study design and analysis of findings.

The problem with criteria-based checklists is that they do not specify *how much* rigour, reflexivity, or credibility constitutes high quality qualitative research. Some qualitative researchers reject the principle of criteria and checklists and highlight that formalised criteria can be overly prescriptive (Bochner 2000; Seale 1999; Schwandt 1996) or

impossible to quantify and that quality in qualitative research is more visceral and iterative than a checklist allows for. Flick (2018) therefore advocates not looking for new or more criteria, or the one set of definitive criteria, but seeing quality issues as something to manage, develop and demonstrate throughout the process. For example, in co-creation methods such as co-design, the findings from each round of data collection are analysed and re-presented in the next round which allows for data checking and participant feedback during the data collection process rather than just at the end.

Bochner (2000) states that criteria are empiricist and unhelpful when applied to new or emerging qualitative approaches. Whilst arguing for less use of criteria-based approached, and more awareness based approaches to assessing quality, Seale (1999), similarly to Flick (2018) acknowledges the purpose of considering quality and methodological issues is to raise awareness in the researcher of the implications of methodological decisions in the research process.

Tracy (2010) developed a model that is expansive and flexible (see Table 7), distinguishing between the means (methods and practices) and the ends (outcomes) and one where it is possible to identify universal characteristics of high quality qualitative research, even if the means to achieve this vary. In contrast to Creswell (2007) who developed specific criteria for each qualitative research tradition, Tracy states that it is possible to identify the common end goals of strong research and the variant methods by which these goals are achieved (Tracy, 2010: 3).

Table 7 Eight 'Big-Tent' Criteria for Excellent Qualitative Research (Tracy 2010)

Criteria for quality (end goal)	***Various means, practices, and methods through which to achieve***
Worthy topic	The topic of the research is • Relevant • Timely • Significant • Interesting
Rich rigor	The study uses sufficient, abundant, appropriate, and complex • Theoretical constructs • Data and time in the field • Sample(s) • Context(s) • Data collection and analysis processes
Sincerity	The study is characterized by • Self-reflexivity about subjective values, biases, and inclinations of the researcher(s) • Transparency about the methods and challenges
Credibility	The research is marked by •Thick description, concrete detail, explication of tacit (nontextual) knowledge, and showing rather than telling • Triangulation or crystallization • Multivocality • Member reflections
Resonance	The research influences, affects, or moves particular readers or a variety of audiences through • Aesthetic, evocative representation • Naturalistic generalizations • Transferable findings
Significant contribution	The research provides a significant contribution • Conceptually/theoretically • Practically • Morally • Methodologically • Heuristically
Ethical	The research considers • Procedural ethics (such as human subjects) • Situational and culturally specific ethics • Relational ethics • Exiting ethics (leaving the scene and sharing the research)
Meaningful coherence	The study • Achieves what it purports to be about • Uses methods and procedures that fit its stated goals • Meaningfully interconnects literature, research questions/foci, findings, and interpretations with each other

As a novice researcher, this is an important part of learning and development. Tracy (2010) likens the use of a framework of criteria to learning a craft or skill, and as a novice, doctoral researcher, the eight 'big-tent' criteria offer a helpful framework for reflecting on the quality of the research in Chapter 7 (Discussion). Tracy's criteria were adopted for this study to provide the researcher with a framework to ensure rigour and authenticity throughout the study.

To what extent the study met the eight criteria will be discussed in Section 7.5.2.1 (Reflections on Quality) in Chapter 7 (Discussion), but also considered throughout the reflective parts of the Discussion. A table is included in Section 7.2.5.1 (Reflections on Quality) to highlight how the quality framework has been met and to signpost to the relevant sections where quality issues have been addressed within the thesis as a whole.

4.5 Ethical Considerations

As the topic of the research concerns PEOLC for a potentially vulnerable group, those with SMI, there were many ethical issues to consider throughout the planning and delivery of the study and multiple approvals were obtained. This section outlines some of the key ethical considerations and details the different approvals which were in place. Further details of procedures for maintaining anonymity, confidentiality and protecting data are included below in Section 4.7 (Methods) and in the Research Protocol in Appendix 2..

The study involved interviewing and working with participants with a range of possible vulnerabilities. Patient participants had diverse histories of mental and physical ill health and wide-ranging experiences of accessing healthcare. In addition, each individual patient participant had a unique response to understanding and processing their situation, and their way of acknowledging and processing a terminal diagnosis varied greatly. Conversations about death, dying and mental ill health can be emotive (Kubler-Ross 1969) for all participants and it was necessary for the researcher to approach interviews and workshops sensitively. All participants were provided with an initial letter of introduction to the researcher and the study, a more detailed Participant Information Sheet (tailored to patients, carers and clinicians) for each part of the study and a consent form (copies of all documents are included in the Research Protocol in Appendix 2).

At the beginning of each interview and each workshop, participants were reminded that they could withdraw from the study at any time without negative impact on their clinical care. Participants were informed about how their data would be used and at what point

it would be impossible to remove their individual data from the research study. Details of support services appropriate to each participant type (patient, carer, clinician) were made available to all participants (copies are included in the Research Protocol in Appendix 2.

In addition, the researcher is an experienced clinician in both PEOLC and mental health and works with the patient group in clinical practice. The researcher is experienced in working with individuals and running groups where distressing or emotive material is processed, made himself available to participants at the end of each interview or workshop to de-brief and was aware of when it was necessary to refer a participant for additional support. In reality, this did not arise in the research process. Patient participants all consented to their care co-ordinator being informed of their participation in the research study, so they could also be contacted if patient participants found interviews or workshops distressing.

To protect patient confidentiality, and in acknowledgement of the fact that some conditions are rare, the specific condition a patient presented with was removed from interview transcript and replaced with a general description i.e. neurological condition, cancer or long-term lung condition. All transcripts were anonymised, and details of place and institution names were removed.

The literature review (Blackwell et al. 2017; Borgstrom and Barclay 2017; Cooper, Gillmore and Hogg 2016; Springham and Robert 2015) had highlighted that some clinical staff may find participating in co-design processes intimidating or feel fearful of expressing their views, particularly when the aim of the research is to improve practice, and discussions of under confidence, poor practice or situations where care could have been approved are likely to arise. This contributed to the decision not to use video-recording in the co-design process but to adopt a co-design method which uses the artefacts created in the workshops as the ‘data’ rather than audio or video transcription of the workshop itself.

It was anticipated that the issue of mental capacity and how it should be assessed, whether it may be fluctuating, and whether perceived lack of capacity would stop some participants being identified by their care co-ordinators, would arise. A detailed section of the protocol outlined the processes for assessing mental capacity. This study did not aim to identify or work with patients that lack capacity. However, the earlier literature review (Jerwood 2016) had highlighted that assumptions of lack of mental capacity are commonplace when working with both dying patients and people with SMI and are one of the barriers to delivering effective end of life care. The ethics committees did not in

the end raise this as an issue or concern and were satisfied with the measure put in place, but early consideration of anticipated issues was beneficial in developing the design and protocol to mitigate against any risks.

4.6 Ethical Approvals

Ethical approval was granted at several levels. As participants were patients, carers and clinical staff, and interviews and workshops were held on NHS and non-NHS premises as well as in participants' homes, multiple organisational approvals were obtained. (See Figure 8 for list of organisations and Appendix 3 for approval certificates and letters).

Table 8 List of ethical and governance approvals obtained

Organisation	**Type of Approval**
Coventry University	Ethical Approval, Sponsorship and Indemnity
NHS Research Ethics Committee	Ethical Approval
Health Research Authority	Governance Approval
John Taylor Hospice	Organisational Support and Approval
Birmingham and Solihull Mental Health Foundation Trust Research and Innovation Department	Organisational Support, Governance and Ethical approval
2Gether Mental Health Trust	Governance and Ethical Approval
West Midlands Clinical Research Network	Approval to circulate research documents for recruitment to GP practices and through local networks

Ethical approval was granted by Coventry University and an NHS Research Ethics Committee. Overall, governance approval was obtained from the Health Research Authority. Birmingham and Solihull Mental Health Foundation Trust provided governance approval and review at local level. 2Gether Mental Health Trust provided ethical and governance approval as a research site. John Taylor Hospice provided organisational support to the study and permission to recruit participants. The call for participants was circulated through social media (Twitter and Facebook) on a variety of local end of life care and mental health forums.

4.7 Methods

This section gives an overview of the rationale for the choice of research methods. The process of data collection and analysis are discussed fully in Section 4.9 and Section 4.10) later in this chapter.

4.7.1 Interview Methods

Interviews were chosen to gain the views and experiences of patients and their carers and formed the first stage of the co-design process. Interviews allow researchers to develop an understanding of how people perceive things, what their experiences and stories are, and how they can illuminate a research question or topic (Silverman 2016). A focus group could have been chosen instead but given the sensitivities of some of the possible interview content, and the poor physical and mental health of some participants, attending on set days or set times would have been difficult. Therefore, it was decided that interviews would offer a safer, more secure space for patients and carers to tell their stories. The researcher also knew that this would be a challenging group of patients to identify and locate and was keen to build as much flexibility into the research design as possible.

That said, it was also important to recognise that some participants may have felt intimidated being interviewed alone, particularly by a lone male researcher, so a flexible interview design was created (see Figure 5) which allowed the patient participant to choose whether to be interviewed on their own, with a carer present or in a small group with other patients (as long as they met the inclusion criteria). This part of the design was included in direct response to feedback from a service user who attended a drop-in consultation event during Dying Matters week who pointed out that sometimes people with poor physical health supported each other and felt closer to other service users rather than friends or family.

The research design illustrated below (see Figure 5) deliberately allowed flexibility in sample size, structure and format of interviews to increase the participatory element in this stage of the study.

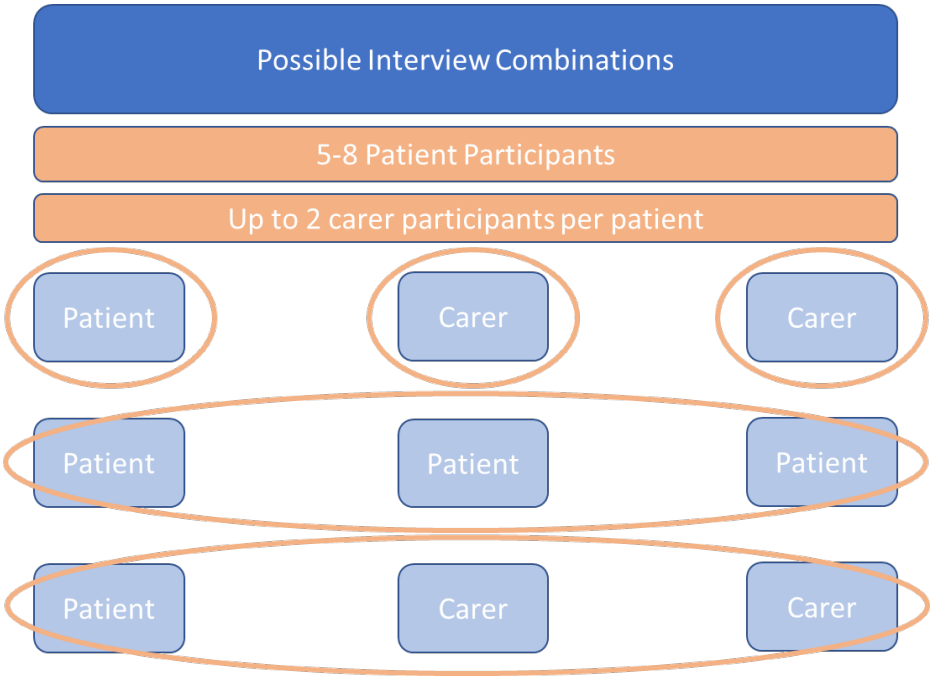


Figure 5 Interview Design

The role of the interviewer was to create a relaxed, informal atmosphere, where participants felt able to share difficult and emotive experiences, rather than to obtain answers to standard questions. This was informed by the participatory underpinnings of the research philosophy and the researcher's desire to break down inequity between the researcher and the participant. As the interviews were designed to explore a particular set of experiences, a semi-structured interview schedule was used to guide the interview that allowed for a degree of flexibility to enable the participant to share any relevant experiences and for follow-up questions to be asked as experiences emerged from the interviews (Rubin and Rubin 2011). The interview schedule was a guide; not all questions were asked in the same order, or to all participants, but instead the schedule served to prompt the interviewer and the participant.

4.7.2 Co-Design Methods

As initially discussed in Section 3.1.1 (Co-creation Methods – Setting the Scene), co-design methods were chosen for the research to ensure that the process of developing a resource which aimed to improve care involved those who will use and benefit from it. Participants in the co-design workshop stage of the study included patients, carers and professional clinical staff from a range of backgrounds (see Table 12 Interview participant profiles).

The findings of the literature review highlighted that whilst co-design has not yet been used in the improvement of PEOLC with this particular patient group, it has been increasingly used in both mental health and PEOLC settings for service redesign, resource development and service improvement. Co-design methods were found to increase engagement, create greater equity between different types of participant and between participants and researchers, and give voice to patient and carer experiences.

Co-design is defined by Macdougall (2012) as 'an attempt to define a problem and then define a solution' (Macdougall 2012: 2). Sanders and Stappers (2008) define co-design as a specific instance of co-creation. Co-creation is described as 'any act of collective creativity, i.e. creativity that is shared by more than two people' (Sanders and Stappers 2008: 6). Co-creation and co-design are becoming more common within healthcare settings beyond their design-based origins, with designers working in partnership with clinicians and patients to solve healthcare problems and develop solutions in collaboration (Boyd et al. 2012; Sanders and Stappers 2014).

Co-design methods draw on participatory methodology by bringing together groups of participants to work together on designing a solution to a problem. In healthcare settings this often involves patients, families, carers, clinical staff and other health or social care professionals. Depending on the nature of the question or problem, different groups of stakeholders are invited to participate. Methods of data collection may include focus groups, workshops, photography projects, blogs, diaries and mapping processes (Bergold and Thomas 2012). Creative and visual methods are used to broaden the range of ways participants can participate and to encourage people to tell their stories and communicate their experiences (Sanders and Stappers 2014). Some groups or individuals may find verbal communication challenging, and organisational hierarchies may impact on participants' willingness to contribute to traditional verbal discussions or meetings. Creative methods allow participants to use imagery and symbols to convey knowledge, rather than just verbal discussion or written communication. Asking participants what they want can lead to a limited discussion based upon what they believe is possible, or currently available. Using creative methods within a co-design process encourages and enables participants to visualise, imagine and convey ideas and concepts, leading to shared language and new understanding (Hagen and Rowland 2011).

Evidence-based co-design (EBCD) is a specific approach with wide application in healthcare internationally (Donetto, Tsianakas and Robert 2014; Robert et al. 2015) and

was considered as an approach for this study. Developed over ten years ago in the UK, originally as Experience-Based Design, and later rebranded as Evidence based co-design to emphasize the collaborative aspects, EBCD brings together four elements into one approach: participatory action research, user-centred design, learning theory and narrative based approaches (Robert 2013). Although often described as a cycle, EBCD is a linear approach with six stages (Bate and Robert 2007; Robert 2013):

1) Setting up the project
2) Gathering staff experiences through observational fieldwork and in-depth interviews
3) Gathering patient and carer experiences through observation and filmed interviews
4) Bringing staff, patients and carers together in a co-design event, using edited 'trigger' films of patient narratives to identify priorities
5) Sustained co-design work in small groups to explore the priorities
6) A celebration and review event

More recently, in response to the criticism that EBCD is time consuming, research carried out by Locock et al. (2014) explored how the EBCD process could be made more time efficient. Accelerated EBCD uses archive films to trigger discussions (taken from www.healthtalkonline.org) and found that using archived films does not lessen the impact of the EBCD approach. However this is dependent on there being an archive of films to suit the research question or phenomenon under study.

As highlighted in Chapter 3 (Literature Review), the EBCD toolkit was created by The Kings Fund to assist researchers and healthcare staff wishing to use co-design approaches in structuring the design and delivery of the project. It uses a structured, staged approach to the exploration, collection and sharing of data amongst participants. The Toolkit offers step by step guides to the stages of EBCD. Each step is illustrated with films, written guidance and downloadable templates to guide the researcher through the process. The toolkit also provides guidance about adapting the process to suit different clinical settings and budgets. The toolkit is freely available and now hosted by the Point of Care Foundation (www.pointofcarefoundation.org.uk) who provide training courses for researchers and professionals each year. Donetto, Tsianakas and Robert (2014) reviewed the implementation of EBCD and found that 45% of projects had used the toolkit, but 55% had used the EBCD approach without it. Some projects which did

not use the toolkit used other resources instead, but reasons for this were not included. The toolkit offers guidance to a specific approach to co-design which has found to be useful in many healthcare service improvement projects.

However, the literature review findings highlighted a tendency to an over-reliance on EBCD as a method because of the existence of a toolkit and an explicit structure (Borgstrom and Barclay 2017). Whilst it was important to offer a structured approach to the co-design process, some of the limitations of EBCD were identified early on in the scoping process. The use of a trigger film may have been problematic or distressing for the participant cohort. Some patients with terminal conditions are not comfortable being filmed due to changes in appearance. This is also true of some mental health service users who may find the filming process intrusive. However, the literature highlighted that the resistance in EBCD to the filming process often comes from clinicians. Sometimes it does not feel safe to share actual views and experiences on film. Some clinical staff attended with their line managers or were mindful of organisational dynamics. The presence of filming may have negatively affected the quality of the discussion and the design process. In addition, a core aim of this study was to bring together and create equity between patient and clinician participants. EBCD involves creation of patient trigger films which are then shown to clinicians, rather than bring the groups together from the start. EBCD does not offer the iterative, creative process which the research questions require.

Instead a structured, iterative, creative co-design process was developed for the research study. The process is described in Figure 6. The process is illustrated and discussed more fully in Section 4.9 (Data Collection).

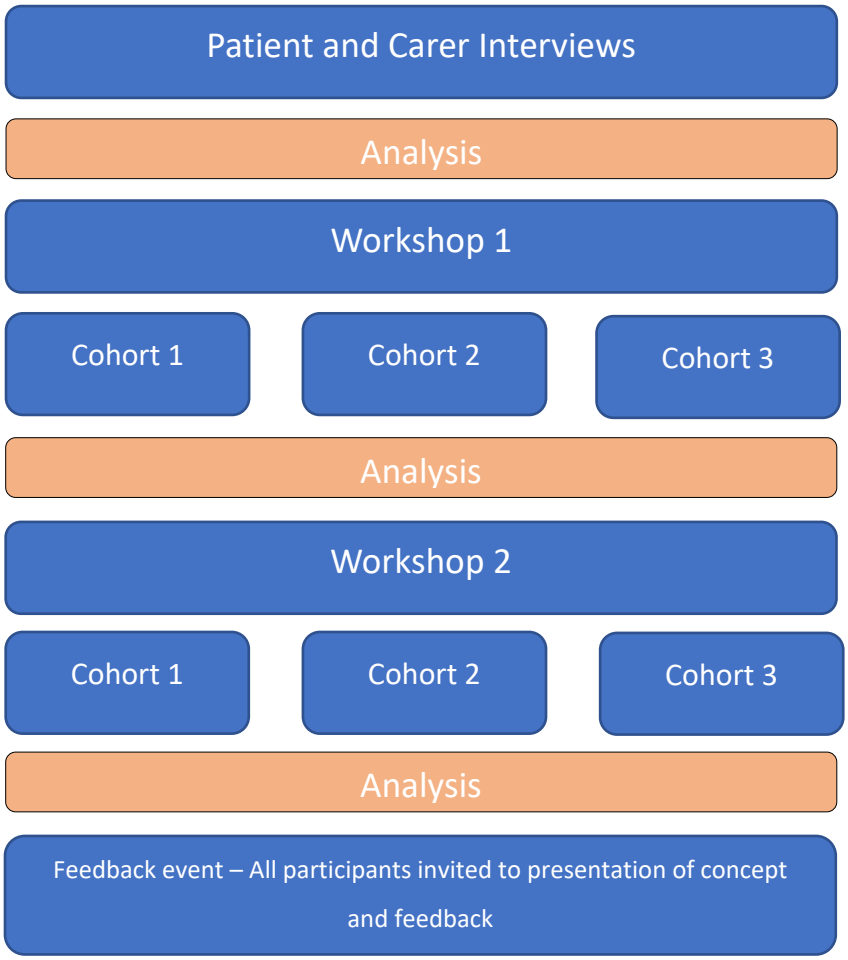


Figure 6 Co-design process

4.8 Sampling and Recruitment

4.8.1 Patient and Carer Interviews

The first aim of the study was to understand the experiences of a specific group of patients, and their carers, so purposive sampling was used to identify interview participants who met the inclusion criteria. Purposive sampling allows the researcher to identify a specific group of participants to take part in a study (Hicks 2009). There has been no research carried out previously with patients who have both SMI and a terminal condition; however, there have been limited studies which asked people with SMI about their views about their end of life care in principal (Foti et al. 2005; Sweers et al. 2013). However, the aim of this study was to obtain the views of patients with direct lived experience of both conditions and to include these patients in the design of a potential resource. Recruitment and sampling strategies needed to ensure that appropriate

patients were informed about the study. Due to the combination of conditions, the intended participant group can be hard to reach and can find it hard to participate in research studies due to fluctuating mental and physical health.

As highlighted in Chapter 2 (Contextual Background), it was already known that people with SMI do not receive good PEOLC, so recruiting solely from hospice settings would not have identified the desired patient group. It was important to identify those patients who had not accessed services, as well as those who had. The researcher therefore asked clinicians within both mental health and PEOLC services to circulate information about the research study directly to patients, in clinics, waiting rooms and multi-disciplinary meetings, as per the research protocol and ethical approvals. Recruitment materials were also circulated by the researcher to the service user leads within the participating organisations, through social media (Twitter and Facebook), patient and carer groups, and via the research teams within each organisation.

There are conflicting views about sample size in qualitative research. The concept of saturation, in other words continuing to collect data until no new themes are developed, is often cited as the way to define sample size (Bowling 2014). This is as opposed to quantitative studies, where a percentage or power sample size is calculated. The goal of achieving saturation is used to justify wide ranging sample sizes in qualitative research (Green and Thorogood 2010; Jolley 2013); however, given qualitative studies seek to understand human experiences and views, it is also problematic to claim to have reached saturation. In a recent conference presentation, Sally Thorne highlighted the problem with claiming saturation has been achieved: ‘it [data saturation] is absolutely antithetical to applied health disciplines…would we trust a health professional who told us there was no more information to be found?’ (McDougall 2017:4). It is also problematic in a study of this size because the researcher must analyse data whilst collecting data. If saturation is to be established, if this is indeed possible, data analysis must be ongoing. The time constraints on the study would have made this problematic.

Rather than set out to achieve data saturation, the aim of the interviews was more exploratory. There have not been any previous studies, particularly in a UK healthcare context, which explored the views and experiences of this patient group. The aim was to carry out semi-structured interviews which allowed for themes to be developed to inform the second part of the co-design process, but also to inform practice in their own right. The sample was relatively small, in part because the patient group were hard to identify and in part due to the resource constraints of a single researcher. A sample size of 4-8

patients had been decided based upon accessibility, resources, time and scope of study (Baker 2012). As the research design encouraged patient participants to suggest members of their informal care networks (ICN) to participate, a limit was set to ensure the researcher has sufficient time to carry out interviews and analyse the data. Each patient participant could nominate up to two ICN members. So, a flexible sample range of up to 24 interviews could have been carried out if every patient participant nominated two carers. This was not anticipated, but it was important to agree upper limits that were realistic at the planning stage of the study.

Inclusion and exclusion criteria were developed to ensure that appropriate participants were approached. This was especially important given that the topic of the study is often misunderstood: what constitutes PEOLC, what a life-shortening or terminal illness is and what constitutes severe mental illness are all possible confusions that could have led to the wrong participants being approached. Inclusion and exclusion criteria are outlined in Table 9.

Table 9 Inclusion and Exclusion Criteria Interviews

Inclusion Criteria and Exclusion Criteria for Interviews	
Included	• Adults who have a diagnosis of a mental illness and are patients within mental health services. Diagnoses may include psychosis, schizophrenia, depression, personality disorder, bi-polar disorder, and anxiety disorders, which cause the patient to be cared for in mental health services; and a diagnosis of a co-existing life-limiting or terminal illness. Individual conditions would be too numerous to list, but conditions which can be expected to shorten life which may include cancers, heart disease and lung diseases including COPD, neurological conditions such as multiple sclerosis and motor neurone disease and other life-limiting and terminal conditions. • Members of patient participant's informal care network (as agreed with the patient) will be invited to take part. This could include family members, close friends, a neighbour, work colleague or member of a faith community who is involved in the care and support of the patient. • Carers of patients who meet the above criteria but who have already died or are too unwell to participate in the study. • Able to give written informed consent to take part in the research.
Excluded	• Patients whose mental ill health is managed solely within primary care. Patients who have developed mental illnesses such as anxiety and depression *following* terminal illness diagnosis. • Patients who have never been cared for in mental health services. Patients without a life-limiting or terminal diagnosis. • Patients who unable to give informed consent or who lack mental capacity or who are unable to participate in structured interviews by reason of detention in services or where participation would cause harm or risk of relapse. • Patients with no experience of the subject matter of the research. • Patients whose only diagnosis is dementia. • Paid care staff or professionals involved in the patient's care and support.

4.8.2 Co-Design

The aim of the co-design process was to bring together stakeholders to work together to co-design the concept and content of a resource. Clinicians encountering this patient group work in many different care settings. PEOLC is multi-disciplinary and cross-cutting in its nature and people with SMI have a wide range of additional physical health conditions. The stakeholders ranged from researchers to patients and carers to clinical staff from mental health services and from PEOLC services as well as other healthcare staff who come into contact with patients with SMI and terminal illnesses, for example acute care and primary care staff. The sampling frame was deliberately broad in relation to the potential audience of end users. Again, sample size was influenced by the desire to ensure a range of experiences, not to engage solely with people with positive views to share, or only with one or two staff groups for example. The same strategies as interview recruitment were used: circulation of publicity materials via email, intranets, through the Clinical Research Network, via clinical teams and through social media forums.

The aim was to recruit three cohorts of participants, each being required to attend two workshops and a feedback event. A balance of types of participant was required to make sure each workshop had a mix of participants. Each workshop could accommodate up to 16 people. In a similar way to focus groups, there is no pre-determined size for a co-design workshop group. In this case, the balance of participants was the main goal, not a specific group size. However, it was important to make sure the group size was not so big that it could not be facilitated effectively (Sim and Wright 2000). The inclusion and exclusion criteria for the workshops are outlined below in Table 10.

Table 10 Inclusion and Exclusion Criteria - Workshops

Inclusion Criteria and Exclusion Criteria for Co-Design	
Included	• Patients eligible for inclusion based on criteria for interviews and in addition, members of their informal care network. • Family members or carers of deceased patients, or those too unwell to take part, who would have met the criteria for inclusion in interviews. • Clinicians from mental health services. Clinicians from palliative care or end of life care services (community, hospital or inpatient). • Other clinical staff who have contact with patients who meet the criteria for interviews, such as care home staff or primary care staff. • Able to give written informed consent to take part in the research.
Excluded	• Participants who are unable to consent to participate, lack mental capacity or who are unable to attend the location of the co-design groups. • Patients, family members, carers or clinical staff who have no experience or contact with the patient cohort the research study concerns. • Patients, family members or carers, clinical staff whose only diagnosis or experience is dementia.

4.9 Data Collection

This section describes the process of data collection across all the stages of the co-design process.

4.9.1 Interviews

The research design allowed for patient participants to be interviewed at home or in another convenient location suitable for an interview. Participating organisations agreed to provide room space where necessary. To make sure the design was as inclusive as possible, the research design also allowed patient participants to identify members of their informal care network to be interviewed, either with them in a small group interview, or separately.

Interviews were audio recorded and the interview schedule was used to ensure the interviews covered the research topic and did not digress into wider issues about mental health, physical health care or other topics. Following the ethical procedures within the research protocol, each participant provided written consent to participate having read the Participant Information Sheet (multiple versions for each type of participant had been prepared for the Ethics Application and are included in Appendix 2 Research Protocol).

4.9.2 Workshops

Two rounds of workshops were held with each of the three cohorts of participants. This section describes and illustrates how data was collected in each round of workshops.

2.1.1.1 Role of the co-facilitator

Each workshop was facilitated by the researcher and a co-facilitator. The co-facilitator was an advisor on the supervisory team, experienced in co-design methods. The role of the co-facilitator was to take notes, to support the arrivals into the workshop and to support participants who might have needed to leave the workshop, all in order to allow the researcher to take the role of lead workshop facilitator.

2.1.1.2 Workshop 1 – Cohort 1,2,3

The first workshop focused on asking two key questions:

- What should form the content of the resource?
- What format should the resource take?

Participants were presented with a summary of the findings of the previous clinician study and literature review and indicative themes from the patient and carer interview analysis. These were supported by quotes from the interviews in the form of a short presentation, which had informed the research questions, study aims and objectives. Creative co-design methods were used to aid the discussion and images and artefacts formed the data from the workshop (see Figure 8).

As identified in the literature review, creating space for co-design is important. Terp et al. (2016) refer to the importance of creating a space or environment for co-design to take place, so the room where the workshops took place was prepared in advance. Resources to support data collection included paper, card, marker pens, post-it notes, stickers, and basic art and collage materials, all of which were used to help create the space. All information and slides were printed or drawn and put up on the walls to allow participants to refer to them throughout the workshop. This was to support the iterative nature of the co-design process and to provide participants with information which was known to the researchers, such as previous research findings and contextual information. This helped participants to focus on the workshop tasks and move the process forward. The background to why a resource was being developed to improve clinician confidence, and why it was being co-designed, as well as what the research was not aiming to do, were other examples of the kind of background information that was shared. In addition, a summary of the poor experience of end of life care of people with SMI and some initial findings from the patient interviews were shared.

Each workshop was presented with the same questions and blank card boards to work on. This allowed the researcher to analyse the differences between the different cohort responses. The data was analysed in between workshops to inform the subsequent workshop. This allowed for an iterative, co-design process to occur, and for each group to benefit from previous one. Although the explicit aim of co-design is not to achieve consensus, like in a Delphi study, there is an element of building consensus as the design process occurs (Iliffe et al. 2013; Pinfold et al. 2015). Therefore the analysis of co-design data must be done differently to other qualitative data and this is discussed further in the data analysis section below. The analysis of the first round of workshops summarised the data collected and then informed the design of the second round of workshops. The analysis process for the data is explored further in Section 4.10 (Data Analysis).

2.1.1.3 Workshop 2 – Cohorts 1 + 2, 3

The second workshops focused on three key areas:

- Prioritising content (summarised into themes from first workshop)
- Using paper prototyping to begin to develop the concept of the resource (based upon prioritised content) – thinking about format considerations
- Discussing sources of knowledge and information for clinicians – thinking about legitimacy, reach and reliability.

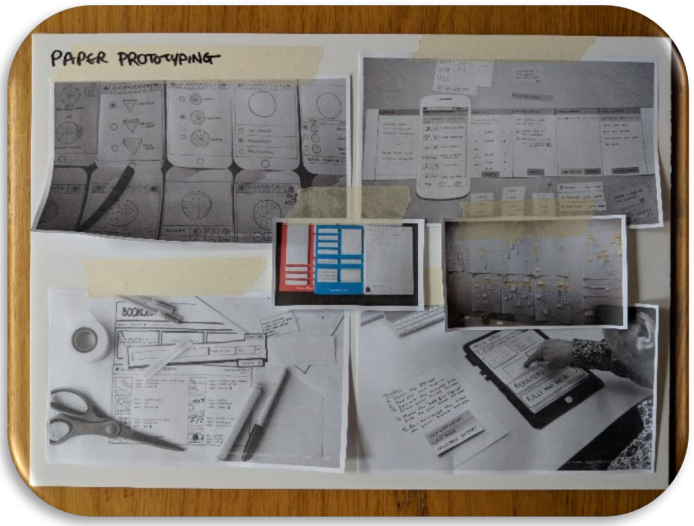


Figure 7 Paper prototyping method

Paper prototyping (see Figure 7) is a simple technique used by software developers to create very early stage prototype of apps and websites and other resources (Snyder 2004). It uses cheap and simple materials (paper, card, scissors, markers, tape etc.) to allow participants to create sample web screens of app designs and other products to tests usability without large financial and resource investment. The advantage of paper prototyping is that is uses materials that are familiar to all users, they are low cost, and they encourage users to move away from verbal theoretical discussion into practical making and designing (Nessler 2016). Users can consider how a product will look, feel and function as well as thinking about content. Paper prototyping is useful to move discussions away from theoretical or problem-focused thinking and into experimental, playful creative solution focused activity (Snyder 2004).

Figure 8 Paper prototyping in workshops

2.1.1.4 Discussing Sources of Knowledge and Clinical Information

The final part of the workshop involved participants thinking about where they seek information and knowledge from, and which sources feel reliable and legitimate. The groups were asked to think about where they feel they should get information and where they actually go for information to see if there were differences. Comments on the different locations and sources of information and how participants feel about them were also collected along with suggestions of useful information or resources which already exist. This data was analysed to inform the development of the concept of the resource and is presented in Chapter 6 (Findings).

4.10 Data Analysis

The data collected consisted of interview transcripts and artefacts from the workshops with additional observational notes and annotations made by the researcher and co-facilitator. The decision was taken by the researcher to carry out the analysis of both sets of data manually rather than use a software tool such as NVivo. Manual analysis of the data allowed the researcher to be fully immersed in the data. Photographs of the data collected allowed the data to be captured in its raw state, then physically analysed, moved, clustered and sorted as themes are identified. As an art psychotherapist, the researcher is familiar with the handling of artefacts and images, and the embodiment of the maker in the image or object they make. In the same way that quotes are often used

to illustrate a theme or code in qualitative data, photographs of data items are included in the findings where they add meaning or context to the code or theme. Manual analysis allowed the researcher to remain in close contact to the data set and the visceral qualities within it.

As the research design involved semi-structured interviews and workshop data, an analysis method which is flexible and not tied to a particular research methodology was required. Braun and Clarke (2006) state that there are broadly two types of qualitative analysis. The first type is those which are tied to a particular epistemological or theoretical position such as Interpretive Phenomenological Analysis (IPA) or Conversation Analysis (CA) where the process of analysis is embedded within the methodological approach. The second type is methods which are independent of a theoretical or epistemological approach and which can be applied across a range of research designs. Thematic Analysis (TA) is a method which is used widely in qualitative research and offers flexibility in how it can be applied and is an example of the second type of qualitative analysis.

Braun and Clarke's (2006) model of thematic analysis was used (see Table 11), which offered a structured approach to the analysis of qualitative data. It was developed to counter the criticism that TA is often a 'poorly demarcated, rarely acknowledged yet widely used qualitative method' (Braun and Clarke 2006: 2). Braun and Clarke argue that it is an accessible and theoretically flexible approach, which is a foundation method for qualitative analysis, useful for early career researchers.

Table 11 Thematic analysis steps

Familiarisation with the data	Transcribing/reviewing data collected, reading transcripts/looking at photographs, initial analysis of visual data items, making initial notes, listening to audio recordings of interviews, reviewing field notes
Generating initial codes	Open coding, attributing codes to all potentially relevant items in the data
Searching for themes	Clustering and sorting codes into possible themes, considering relationship between themes, over-arching themes, sub-themes, identifying which data items have been coded in relation to each theme
Reviewing themes	Reviewing coded data, considering themes, revising coded data which does not fit, re-allocating coded data to a new theme where necessary, devising a thematic map
Defining and naming themes	Identifying the story each theme tells, writing a detailed analysis of each theme, developing titles for each theme

Presenting the data	Writing the story of the data and analysis, evidencing the themes, providing narrative beyond description of the data, presenting the argument in relation to the research questions

The data collected in the co-design process was not conventional transcribed data. It took the form of visual data (see Figure 13 and 16). A thematic analysis method was required which could also be adapted to analyse visual data generated within a group setting. Many researchers using visual data cite different forms of content and thematic analysis in their procedures for coding and creating themes within their visual data, but as the results of the literature review highlight, little has been written about the actual *process* of analysis of visual data in qualitative research (Borgstrom and Barclay 2017). One of the objectives of the study was therefore to contribute to the development of the evidence base for the analysis of visual data.

Kreuger and Casey's Classic Analysis Strategy (2015) provides useful tools and techniques for *carrying out* analysis which were used to complement the model of TA outlined by Braun and Clarke (2006). The method is described as 'a systematic approach to identifying and categorising results which is visual and concrete' (Kreuger and Casey 2015: 35). Ward et al. (2015) provide a useful description of applying the Classic Analysis Strategy to visual co-design data. The process of analysing visual data is similar to analysing interview transcripts: a period of immersion in the data, initial coding, refining codes, developing themes and concepts, reviewing themes and presenting the data. The method is illustrated below in Section 4.10.1 (Illustrated Analysis Process).

An inductive approach was taken; open-coding of all the data was carried out. It would have been possible to take a deductive approach and interview patients and carers using the themes which had arisen from the literature reviews or clinician study already undertaken. However, an inductive approach allowed the themes which were of concern to the participant to be identified (Thomas 2006). This is important when working with a disempowered group, and within a traditionally 'top-down' healthcare system.

As the research method involved iterative rounds of data collection which informed each other, analysis of the data was carried out after each stage of data collection, rather than solely at the end of the data collection process, and each round of analysis informed the next round of data collection. This process is illustrated for information below.

TA is sometimes criticised for simply presenting back the data collected and that the analysis of the data can be weak (Braun and Clarke 2014). In the analysis process, defining, naming and presentation of the themes, in each stage, is important to ensure that the data is not simply described, but that the story and narrative of the data is told. Kreuger and Casey (2015) also highlight the need to consider the process of identifying the significance of themes and sub-themes. In a group setting, particularly in a co-design process, it is not possible, or indeed appropriate, to count the number of times a particular code or theme is mentioned. This is partly because, in qualitative research, frequency is not the only factor under consideration. Many participants may refer to a theme, many times, or one participant may talk at length about a theme for a large part of an interview and this may be as significant or important in the data set as the themes which arise multiple times. This is even more relevant with groups of participants working together, as they are unlikely to record the same issue multiple times, as one or two participants may take responsibility for capturing the discussion, or the group may debate at length an issue before capturing it visually or in writing.

Kreuger and Casey (2015) identify several factors to consider when developing themes which were used to inform the data analysis process.

- *Frequency* – the number of times something is said, and the ability to note when something significant is said which is significant to the study (as described above).
- *Specificity* – consideration of giving weight to specific items or experiences which are described in detail rather than general terms, understanding the underlying issues of factors within the data item
- *Emotion* – consideration of giving more weight to comments or themes where participants show emotion, enthusiasm, passion or intensity in their contributions – something transcripts cannot convey, but which is noticed by the researcher who is present in the group.
- *Extensiveness* – linked to frequency (how many times something is said, which could be the same person returning to the same theme), extensiveness relates to how many different people said something or identified a theme (hence the use of coloured dots to identify whether a theme arose in one workshop or across multiple workshops).

4.10.1 Illustrated Analysis Process adopted for this study

The structure described by Braun and Clarke (2006) was used to support the analysis process (see Table 11) and the techniques for handling data described in Kreuger and Casey (2015) were used to carry out each of the six steps.

2.1.1.5 Interviews

1. Interviews were transcribed verbatim and transcripts were anonymised and prepared for a visual approach to the analysis. Lines were numbered and each transcript was colour coded to indicate whether it was a patient or a carer interview (see Figure 9). Audio of interviews was listed to multiple times to allow the researcher to become immersed in the data.

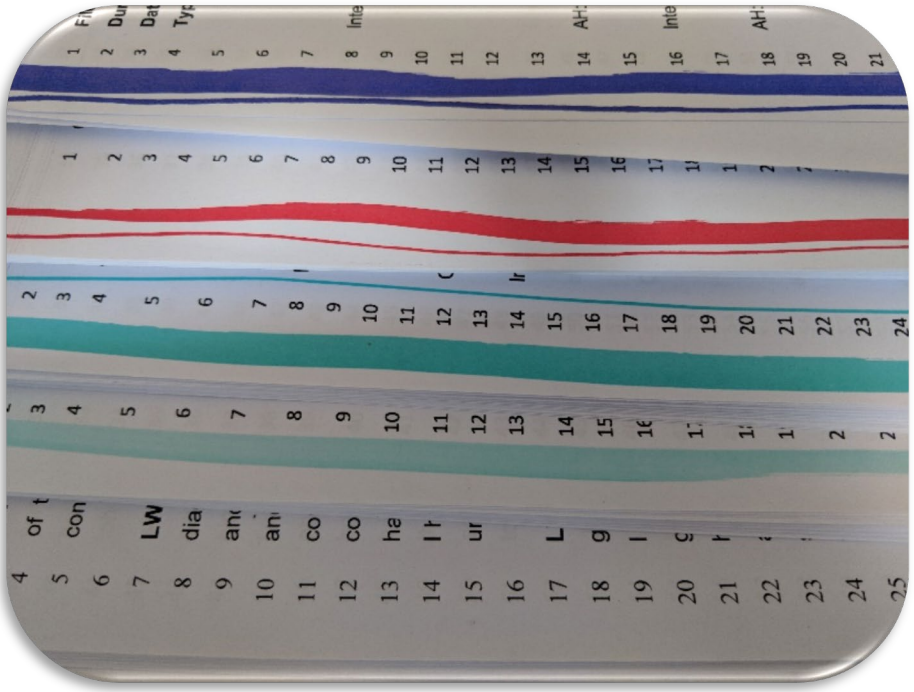


Figure 9 Prepared interview transcripts

2. Each interview was reviewed and initial codes noted (see Figure 10).

Figure 10 Initial coding

3. Each transcript was cut up and each quote or statement was clustered into potential groups of coded data (see Figure 11).

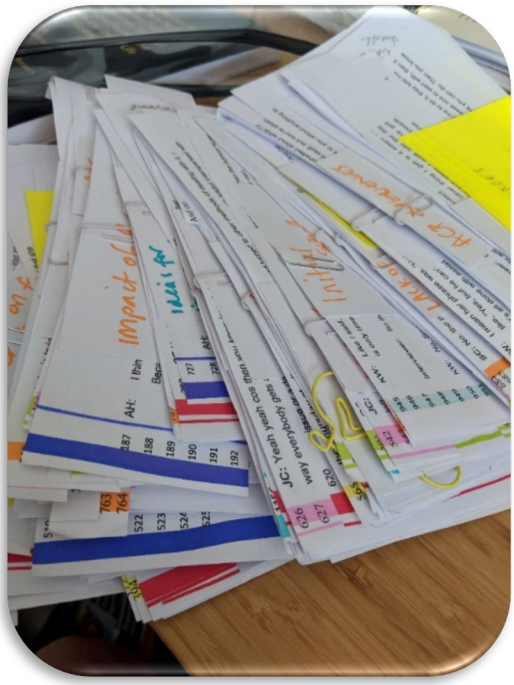


Figure 11 Themed data

4. Each cluster of codes was grouped into a potential theme. Themes were reviewed and refined with the supervisory team (see Figure 12).

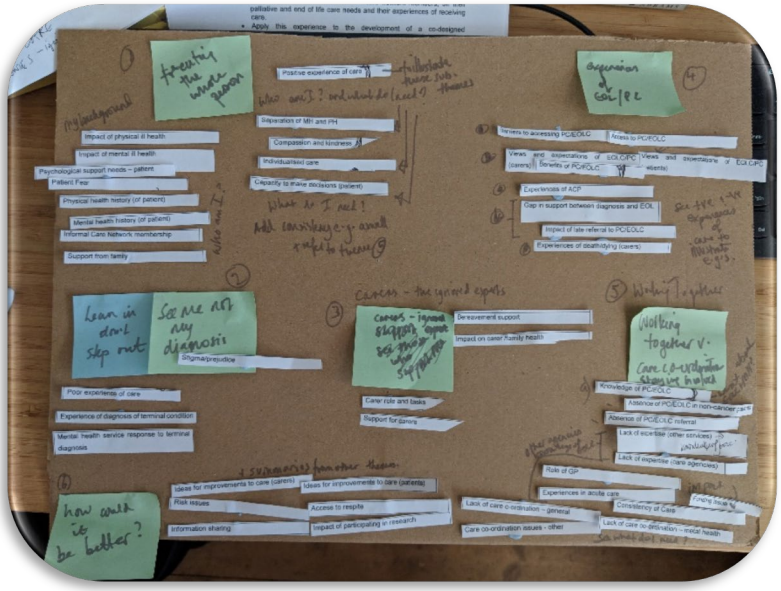


Figure 12 Development of themes

5. An analysis and summary of each theme was developed with illustrative quotes used.
6. The themes analysed alongside each other and presented (see Chapter 5 Co-Design Findings - Patient and Carer Interviews).

2.1.1.6 Workshop 1 – Cohorts 1, 2, and 3

1. Each piece of workshop data was reviewed and photographed in its original form and printed in A3 form for reference (see Figure 13).

Figure 13 Workshop data examples

2. An open coding process was applied. Each coded item was identified and recorded on a table. A coloured dot was applied to each coded item which identified which workshop cohort it had come from. This allowed for the researcher to analyse whether specific themes arose across all cohorts, or within specific cohorts.

3. The boards were dismantled and cut up into individual coded items. Coded data items were clustered into thematic areas and reviewed by another member of the supervisory team (see Figure 14).

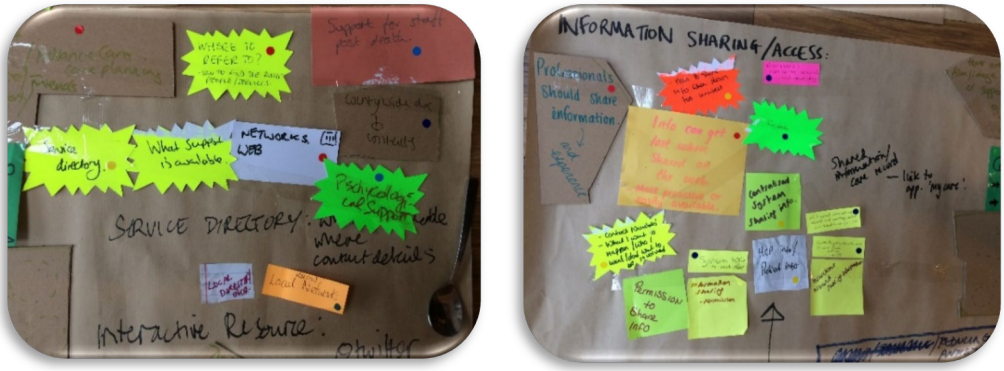


Figure 14 Clustered data themes

4. Themes were identified, refined and the coded data was recorded on to tables. Field notes were referred to during this process to ensure that the observations of the facilitator and co-facilitator were reflected in the development of the themes.

5. Themes were reviewed with members of the supervisory team, revisited by the researcher over a period of several weeks and further refined. Key themes were made into cards to inform the first activity of the second workshop (see

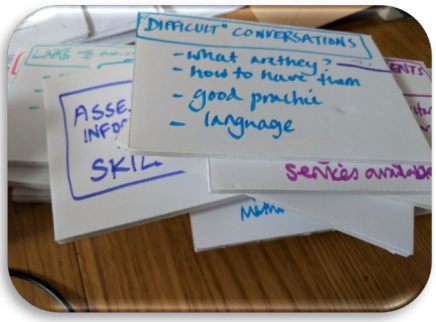


Figure 15 Key theme cards for Workshop 2

6. Analysis and summary for each theme was prepared. A summary of the analysis was collated to be used to structure the next round of workshops.

2.1.1.7 Workshop 2 – Cohorts 1,2, and 3

The data from the second round of workshops was grouped into three main areas.

1. The prioritised content data
2. Paper-prototype data developing the concept of the resource
3. The data collected in response to questions about where clinicians seek information, reliability and accessibility or different sources of information

The same process described above was applied to these sets of data. Where original data sets could not be dismantled and coded, they were photographed, and the same process applied. The original artefacts were photographed in situ to preserve the original primary data.

4.10.1.1 Analysis of Prioritised Content Data

1. Each prioritisation result of the content was photographed.
2. A table was prepared which compared how each group had prioritised data.
3. High and medium priority data was used to inform the next activity in the workshop.
4. These results are presented in Chapter 6 (Co-Design Findings- Workshops).

4.10.1.2 Analysis of Co-Designed Web Screens

1. Each piece of workshop data was reviewed and photographed in its original form and printed in A3 form for reference (see Figure 16).

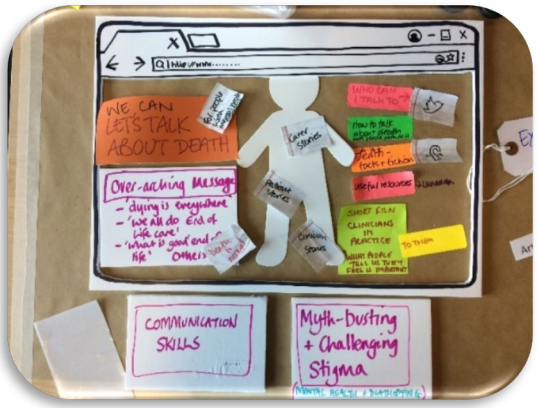


Figure 16 Example of paper prototyping content

2. An open coding process was applied to each data set. Each coded item was identified and recorded on a table.

3. Each screen was analysed and content collated.

4. Themes were identified and refined and the coded data was recorded on to illustrated tables (see Figure 17). Images of original data were used in a similar way to how direct quotes from transcripts are used to illustrate themes. Field notes were referred to during this process to ensure the observations of the facilitator and co-facilitator were reflected in the development of the themes.

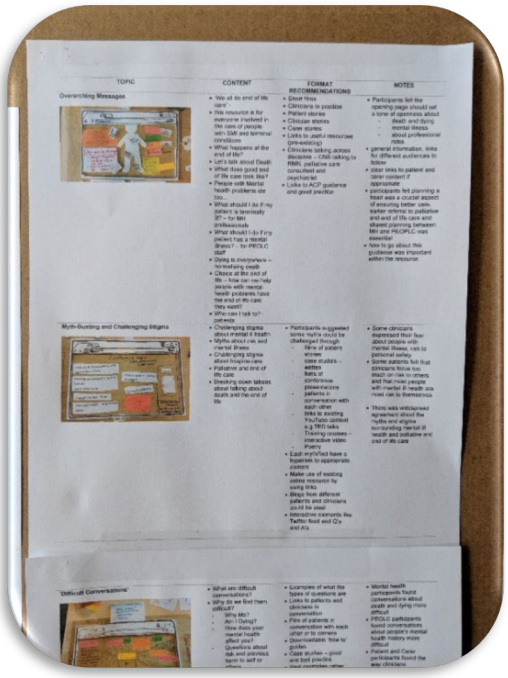


Figure 17 Illustrated co-design data tables

5. Themes were reviewed with members of the supervisory team, revisited by the researcher over a period of several weeks and further refined.
6. Analysis and summary for each theme was prepared. The overall concept of the resource is presented in Chapter 6 (Co-Design Findings - Workshops).

The analysis process was complex and multi-staged. The use of visual data in co-design is becoming more popular, but the methodologies for analysing visual data are still emerging and are yet to be well-defined in the literature. This is further discussed in Chapter 7 (Discussion).

4.11 Chapter Summary

This chapter has described the background and rationale for the methodological choices made by the researcher. The research methods chosen have been critically discussed, the data collection methods presented and an illustrated process of data analysis has also been included. The next two chapters present the findings from each stage of the co-design process.

Chapter 5 Co-Design Findings - Patient and Carer Interviews

The previous chapter described the methodology and methods adopted for the study. Detailed descriptions of how data would be collected and analysed were included. This chapter will present the findings from the patient and carer interviews, the first stage of the co-design process. The themes identified in the analysis of the interview data were then used to inform the subsequent stages of the co-design process as described in Chapter 4 (Methodology -see Figure 4 Study Design Diagram).

Eight interviews were carried out between November 2017 and January 2018. Five with patient participants and three with carer participants (see Table 12 for participant profiles). The final number of interviews was within the range expressed in the protocol and the analysis developed four overarching themes, which are discussed in this chapter.

Table 12 Interview participant profiles

Initials	Participant Number and Patient (P) or Carer (C)	Gender	Age Range	Time in Mental Health Services/cared for person in mental health services	Time with terminal condition	Health conditions list (patient or person cared for by carer)
'Stephen'	P1(P)	m	50-54	30+ years	0-5 years	Anxiety, Depression, Brain injury, Alcoholic liver disease, previous suicidal attempts
'Julie'	P2(C)	f	50-54	5-10 years	5-10 years	Neurological disease, Depression, Anxiety, previous suicide attempts
'John'	P3(P)	m	50-54	30+ years	0-5 years	Prostate cancer, Schizophrenia
'Colin'	P4(P)	m	50-54	20-30 years	10-15 years	Liver disease, Personality disorder, Bowel disorder, Anxiety, Depression, Suicidal ideation
'Bridget'	P5(C)	f	45-49	0-5 years	0-5 years	Non-specified mental illness, Dementia
'Lorna'	P6(P)	f	40-44	30+ years	0-5 years	Schizo-affective disorder, Anxiety, Depression, Bowel disorder, Rare blood cancer
'Jane'	P7(C)	f	60-64	30+ years	0-5 years	Schizo-affective disorder, Anxiety, Depression, Bowel disorder, Rare blood cancer
'Jordan'	P8(P)	m	20-24	5-10 years	0-5 years	Terminal lung disease, Personality disorder, History of psychosis, Anxiety

The findings from the interviews are presented as four overarching themes. Each theme has several sub-themes which include direct quotes from interview transcripts. As outlined, Braun and Clarke's (2006) model of thematic analysis was used for the analysis approach whilst the quality framework of Tracy (2010) was used to ensure credibility in the analysis. Pseudonyms have been used to protect the anonymity of participants. Several rounds of analysis were carried out, and conceptual themes and sub-themes were developed. This is presented as a conceptual framework in Figure 18.

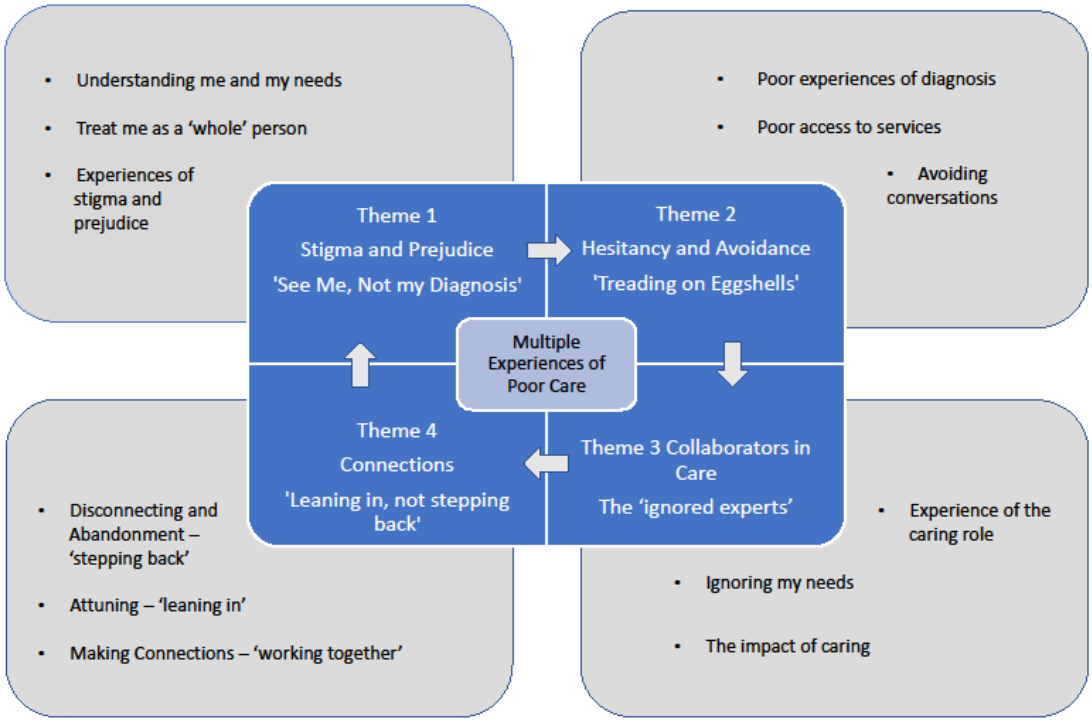


Figure 18 interview Conceptual Framework

Overwhelmingly, participants accounts of their experiences highlighted an absence of care co-ordination, disconnection between services and between patients, carers and healthcare staff. The interviews offered rich descriptions of multiple experiences of poor care, gaps in care, lack of collaboration underpinned by stigma and prejudice of both mental illness and of death and dying. These experiences were compounded by the participants' experiences of prejudice and discrimination within healthcare services and the lack of knowledge and lack of confidence in healthcare staff which led to poor experiences of trying to access palliative and end of life care. The themes are characterised by an overall concept of a void or chasm in care for people with SMI and terminal conditions and their palliative and end of life care needs.

5.1 Overarching Theme 1: Stigma and Prejudice - ‘See me, not my diagnosis’

The first conceptual theme concerns the tension between patient participants’ desire to be seen and treated as an individual and the stigma and prejudice they experience when accessing healthcare services which caused them to feel as though their diagnosis or label defined them. The patients and carers interviewed have experienced the same stigma and prejudice as anyone else living with SMI. However, this theme concerns more specific issues and experiences raised by patient participants in relation to being diagnosed with a terminal condition and having a need for PEOLC in addition to their pre-existing mental health condition. The overarching theme includes three sub-themes; 1) Understanding me and my needs; 2) Treat me as a ‘whole’ person and 3) Experiences of stigma and prejudice. The overarching theme explores the patient and their complex medical presentations, histories and social environments; their expectations of care and their experiences of stigma and prejudice in healthcare services all contributing to multiple experiences of poor care.

Several factors were identified which affected the patient’s willingness and ability to access PEOLC including past experiences in healthcare, the impact of living with complex health conditions, both mental and physical, and the extent of the patient’s informal care network.

5.1.1 Sub-theme 1: Understanding me and my needs

The patient participants interviewed all described a complex history of both mental and physical health conditions. None of the patient participants interviewed had only one mental health condition or one terminal condition. All the patient participants had multiple co-morbid conditions (summarised in Table 11) which have an impact on their ability to engage with healthcare services. All the patient participants interviewed described negative experiences in both mental and physical healthcare services in the past which impacted upon their views and expectations of how they would be treated by PEOLC services. The fear of being treated badly or discriminated against had led to one participant, Lorna, hiding details of her mental health condition to the team treating her cancer, whilst at the same time avoiding talking to her mental health team about her declining mental health, because she feared a psychiatric in-patient admission and felt the ward staff would not be able to support her physical health needs. This led to a lack

of support from both teams involved in her care and no referral to palliative care was able to be considered.

> *'I wouldn't say about the psychosis, if I say anything, I say I've had a bit of depression…I'd be frightened in case they see me as a threat' Lorna 459-461*

> *'I have been sectioned before, but I can't go in again, I can't, they wouldn't be able to cope with this [colostomy] there and if I got an infection or my bloods were out they wouldn't know, they don't have those kind of nurses there, I have to stay at home, I have to – I just say I'm ok when they [mental health team] come…I'd like to talk to someone about it but I'm scared they'll think I'm unwell again' Lorna 780-789*

Another participant, Stephen, described how his mental ill health led to him finding it difficult to keep appointments and build relationships with healthcare professionals;

> *'I think it was probably because I wasn't engaging and keeping appointments, it was probably my fault that I didn't follow it up but I was very ill mentally at the time and it got missed' Stephen 187-189*

One carer participant also described the relationship between her mother's mental and physical health and the relationship between the two.

> *'if she is unwell mentally, she won't cope with dealing with other healthcare staff who have no understanding of her mental ill health – and if her physical symptoms get worse, it exacerbates her mental health, but her mental health team don't seem to have any understanding of this' Jane 311-315*

Participants described a variety of informal care networks and the degree to which care networks are different is important to understand. The carers interviewed cared for a parent or partner. They described their roles as a mixture of emotional and practical support and advocacy. Advocacy was an important factor which the carer participants described and is outlined more fully under Theme 3 Collaborators in Care - 'The Ignored Experts'. All except one patient participant described a lack of support networks, particularly limited were traditional family carers as John stated;

> *'I mean, until, well, I'll be honest, until the hospice did get involved, I felt so isolated, I felt as if I was on my own, there was no help…I have no family.' John 297-299*

The four patient participants who described limited family care networks also included wider, but less established support networks such as neighbours, church members and the local shopkeeper. Family relationships were strained, fractured or very limited.

> *'well, I never really did have a good relationship with the family, my Mum has mental health issues and I don't see my brother or sister because of what's happened' Jordan 130*

> *'the only sister I am talking to lives far away and is incapable of getting down here. She suffers with her nerves…. I've managed to upset my other sister to the point she won't speak to me and my other sister won't either' Stephen 502-506*

Friends and neighbours formed a limited part of care networks for these four patient participants; however other service users were a key element of their support networks as Stephen describes;

> *'it's to people helping each other…I ring him [another service user] and say "are you free?" and I go and we chat for an hour…. we help each other out…when he was away for a week, I did miss him' Stephen481-484*

One participant, Colin, highlighted the difficulties of having support from people who also have their own mental and physical health challenges.

> *'the problem is that when I am ill, he is often ill too – we try and help each other but he finds talking to them [healthcare professionals] really hard too. He wouldn't be able to ring up and find anything out because he is my friend not my next of kin too, I worry about that. I wouldn't want them to ring my family if something happened because we haven't spoken for so many years' Colin 456-463*

This sub-theme is characterised by underlying feelings of fear and of a lack of understanding by clinical staff of the complexity of participants' health needs, but also of their social and family support or lack of support and how their previous experiences in

healthcare may impact upon their willingness or ability to access PEOLC. All participants experienced feeling as though the mental health labels and diagnosis they had impacted upon healthcare staff's ability to see their palliative and end of life care needs.

5.1.2 Sub-theme 2: Treat me as a 'whole' person

The second sub-theme highlights patient participants' experiences of the separation between mental and physical health and the negative impact this has upon their experiences of both mental and PEOL care. All of the patients and carers interviewed felt a level of frustration with healthcare teams not seeing the 'whole person' and feeling as though healthcare staff had a lack of understanding of the impact physical and mental health have on each other and the complexity of each patient's health overall.

All the patient participants interviewed expressed a desire for greater integration between mental and physical health. The separation between services was unhelpful for all participants whose experience was of having to separate themselves into symptoms or body parts. This was unhelpful for the participants interviewed who felt that good mental health included thinking about how mental health and terminal diagnosis (and physical health conditions more generally) impact upon each other.

This was described by Jordan as akin to putting his life in separate boxes;

> *'they [lung specialist team] just want to talk about your physical [health], and they think the mental health is just going to be sorted. They don't want the overlap, if you know what I mean. There is a definite "we deal with this, they deal with that" and it's the same with X [mental health team]..it's really fragmented, like your life is in boxes and they never interlink…it just makes me feel like I have different personalities, you know what I mean, like I am living five different lives at time' Jordan 704-716*

Colin felt as though his physical health needs had been neglected when an in-patient in a psychiatric unit;

> *'I was admitted for six months and while my mental health was stabilising, I was putting on weight, no-one was monitoring my type 2 diabetes and I didn't see the liver team at all during that time. I missed blood tests and there was no referral to the hospital palliative care team*

> *because they thought "oh he is in hospital, they will deal with that" but they [psychiatric unit] don't do any of that' Colin 102-107*

All five patient participants also highlighted the need for compassion and kindness as important to them. This aligned with the need for individualised care. Lorna and Colin highlighted the need for services to spend time getting to know patients with SMI when they are mentally well and not to treat all patients with the same diagnosis the same;

> *'they need to know you personally and not see the bad side cos when I am ill it is frightening, and then they'd understand better' Lorna 612-613*

> *'for them to treat people as an individual, so everybody is unique and different regardless of the diagnosis or symptoms. Each person, although they've got similarities with other people, needs to be treated as completely individual because their experience will be different' Colin 868-872*

Patient participants understood that they may sometimes present with challenging or unusual behaviours or beliefs and that healthcare professionals may find this challenging but urged clinicians to spend time and see beyond the symptoms of the mental health illness. Jordan described this in relation to controlling and anxious behaviour;

> *'when I am frightened I can become very controlling and anxious and want to be in charge of everything. I know some people find this hard to cope with, when I am well I am not like this at all and then I get embarrassed and find it hard to talk about it. One nurse though, she used to sit and talk to me about what would help, and show me my notes and explain things and it really helped, and she reminded me that when I am well I am not like this' Jordan 914-919*

On the whole, participants did not expect clinicians to be experts in all specialisms but suggested that what was more important was their ability to ask appropriate questions of patients and carers, to know when and where to refer for more specialist information and support, but also to ask the patient and not to make assumptions. Colin's comments particularly illustrated this issue;

> *'okay so it's not necessarily about them having lots of information about mental health, and in some ways, it might be better because*

> *they wouldn't make assumptions about different conditions and labels, but really it's about them having the skills to treat you as an individual and ask you...' Colin 780-785*

This sub-theme captures all participants' desire for more integrated care, not necessarily integrated services, but for clinical staff to see beyond their own specialism, and to consider how different aspects of a patient's presentation, medical and social history might be relevant to their current needs. All participants experienced a lack of compassion and kindness which was underpinned by stigmatised views of mental illness, but also due to being a terminally ill patient, which is further highlighted in Theme 2 Hesitancy and Avoidance 'Treading on Eggshells'.

5.1.3 Sub-theme 3: Experiences of Stigma and Prejudice

All of the participants interviewed shared experiences of being stigmatised when accessing healthcare services. This was the case in mental health, PEOLC and other parts of the healthcare system. One of the notable aspects of this sub-theme, (also highlighted in Sub-theme 1, Understanding me and my needs) was the impact previous experiences of being stigmatised had on patients. Where patient participants had repeatedly experienced negative treatment from healthcare services, it made them more reluctant to share information about their mental health with other services. One carer participant, Jane, reflected on whether her mother would share details of her mental ill health with her physical healthcare team;

> *'yeah, yeah, she has been treated differently in the past, I guess that has been her own experience…she has learnt to kind of, you know, "do I tell them or not?" …. some of the stigma and lack of awareness [about psychosis] she has felt from general nurses in the hospital about her mental health…' Jane 383-386*

Lorna and Colin reflected upon living with the stigma of SMI for many years;

> *'there is still a lot of shame, a lot of shame, still a lot of stigma' Lorna 493-495*

> *'if I was in a room with two people with cancer and I'd got mental [ill] health, and there were clinicians or something, the approach would be different…it would be different and I would sense that straightaway, it's hard to put into words, but I get the vibe. I feel it' Colin 948 - 953*

In addition, patient participants talked at length about how they felt they were viewed by healthcare professionals in relation to mental health stereotypes surrounding violence and risk. This was mentioned by all patient participants, and highlighted here by Lorna and Colin;

> *'you see the distance on them, do you know what I mean, as if I was going to go around and poleaxe everybody...' Lorna 452-454*

> *'when I tried to challenge that [reactions between medications], that became a problem, especially in acute [mental health] wards, because then it became non-compliance! Whereas I was a bit anxious and worried about what I was taking, I wasn't being awkward. Colin 350-352*

One way of managing the fear of being stigmatised or treated unfairly seemed to be to subscribe to a hierarchy of mental illness. Patient participants perceived there to be more feared mental illnesses (schizophrenia, schizo-affective disorder, psychosis and borderline personality disorder) and less-feared mental illnesses (such as depression and anxiety).

Patient participants described telling healthcare professionals they had depression as they felt it would provoke a less negative reaction than if they had other conditions. Lorna describes her decision not to disclose her diagnosis of psychosis/schizo-affective disorder;

> *'I don't say I have suffered psychosis, cos I knew, I opened up before and I wasn't treated very nice, you know what I mean? It [Depression] feels less evil than schizo-affective disorder…it's that first word "schizo" – it puts everyone in the frame of mind "oh don't upset her" …we are not all axe grinding psychos…' Lorna 474-478*

Three of the patient participants interviewed had experienced being ignored or 'fobbed off' when presenting with physical ill health symptoms prior to being diagnosed. John's experience echoes the other participants' experience;

> *'I did get to see my GP and I said to him I think I have a problem with my prostate and he said don't be silly you're not old enough, I'm not even going to examine you. So that was a bit annoying cos ten weeks down the line, I found out I've got cancer.' John 369-373*

All three described a delay in receiving a diagnosis due to their symptoms being attributed to their mental illness, known as 'diagnostic over-shadowing'. This phenomenon is well-described in the literature about mental illness and physical health (Noblett, Lawrence and Smith 2015, Royal College of Psychiatrists, 2013). Many patients with physical health conditions report their symptoms being ignored or attributed to their mental ill health. Lorna and Colin describe their experience of diagnostic overshadowing;

> *'two years, two years, I was up and down that hospital…the doctor just kept sending me back and it was awful' Lorna 241-243*

> *'...I felt like I wasn't listened to for a long time and dismissed…I think that was partly because of the borderline personality disorder label as well. I was trying to say things that I thought were relevant to my health and my treatment, but I was either dismissed or they weren't taking it on board. They weren't taking it seriously. I got the feeling it was like "well, what do you know?". Colin 734-740*

The stigma and prejudice experienced by some participants had led to self-stigma, delayed diagnosis which impacted on prognosis, participants feeling fobbed off by services and feeling that they were no more than a label or diagnosis. The prejudice towards mental illness led to their mental health diagnosis being defined as the prominent attribute when accessing other areas of healthcare in relation to their physical healthcare needs and terminal condition.

This overarching theme identifies that what participants were very aware of was the fear that their mental health diagnosis, labels and symptoms, engendered in the clinical staff they encountered in both physical and mental health settings. In addition, the compartmentalising of different aspects of health needs contributed to an overwhelming feeling of being seen as a set of conditions or labels rather than as a person with a need for kindness, compassion and understanding. All of which led to poor experiences of healthcare at a time when good support was needed.

5.2 Overarching Theme 2 Hesitancy and Avoidance - 'Treading on Eggshells'

This overarching theme identifies themes of hesitancy and avoidance, which were common occurrences through participants' poor experiences of how they were treated by different healthcare professionals, in relation to having a terminal condition. There

were numerous instances of clinicians approaching patient participants with SMI with hesitancy or a lack of confidence about what would normally be classed as their usual intervention within their field of practice because of their mental health condition. Conversations about diagnosis and prognosis were avoided or were tentative and hesitant, with participants feeling this was related to a fear in clinicians of how they would react. The stigma and prejudice explored in the previous theme underpins this. Conversations about planning of care, involvement in care and care choices were avoided by professionals in ways that participants felt would not have happened if they did not have SMI. This hesitancy in staff to talk about mental health and terminal conditions is captured by John;

> *'I live with this every day, I know I have mental health problems, I know I have prostate cancer, I know I am dying. It makes me feel better to talk to staff about it, so I know they know what I want to happen. I am just like everyone else. I think the thing that most people suffering with mental health problems don't need but would like, is recognition that they are ill, but not to treated differently because of it' John 591-593*

Jordan explains how both mental health and physical health clinical staff avoided talking him about his PEOLC needs for fear of upsetting him and the impact this had on him;

> *'so like the mental health team don't want to even acknowledge I have this [terminal condition], they just want to talk about my mental health and it's like they don't even see me…and then the lung team gave me this book about what I want to happen to me, but wouldn't talk to me about it and won't even refer me to a hospice team or whatever…they think it will make me suicidal or something when it just makes me feel like no one cares' Jordan 435-439*

There are three sub-themes with this overarching theme; 1) Poor experience of diagnosis 2) Poor access to services and 3) Avoiding conversations.

5.2.1 Sub-theme 1: Poor experience of diagnosis

All the patients and carers identified negative experiences of how their terminal or life-limiting diagnoses were handled which they directly attributed to having mental health conditions. Patient participants described a hesitance or avoidance of sharing diagnosis information with them and experienced a feeling of not being seen as able to cope with

the information and patronising attitudes from healthcare professionals. Colin describes his experience of this;

> *'I had things said to me like "well, we won't do any more tests because tests can be confusing" which I thought was a bit patronising and a bit of a strange comment to make' Colin 181-184*

John described his experience of being told he had metastatic prostate cancer;

> *'so they told me I had cancer then, but they didn't tell me how bad or how good, you know, how the prognosis is. They didn't tell me anything about it, you know, nobody actually sat me down and talked to me, it was all…they gave me some pamphlets and told me to go home and read them and that's basically how I found out' John 313-318*

Carers experience of diagnosis was more related to the lack of support available to the person they were caring for in relation to their mental health needs. One carer participant, Jane, described the experience of her mother, who has been a mental health service user for thirty years, being told she had a terminal cancer;

> *'we were all shocked and upset but my mom reacted in like, a psychotic reaction to it…. and I don't know what I expected but I knew she needed to be seen [by her MH care co-ordinator] and they needed to know what was going on….but it was like "I don't really know much about that so go home and….." you know her reaction was a psychotic reaction, all her delusions and paranoia was coming out, and it wasn't about the actual diagnosis and the actual information we had heard that day, it was pure psychotic stuff……and it was really hard, because I thought there isn't anyone…who can I call?' Jane 462-480*

At a time when this participant most needed support, mental health services withdrew from her leading to both the participant and her family feeling abandoned. Lorna described her need for support at the point of diagnosis and the response of her mental health team;

> *'he [Consultant Psychiatrist] was kind of concerned but said there was not much he could do, my daughter rang up and said I needed support with it [cancer diagnosis] cos it had triggered an episode, and*

> *they said well we aren't qualified to deal with that, and they just backed off, backed off' Lorna 535-538*

One patient participant described mental health services as "treading on eggshells" regarding his physical health needs, and described the withdrawal of mental health services as the opposite of what he needed at the point of diagnosis;

> *'I need them to support me…they [MH service] tread on eggshells about my illness, it's like it makes them just withdraw' Colin 454-455*

The poor experience of being told about a terminal diagnosis, and the unwillingness of clinicians to talk about it to participants left them feeling abandoned and ignored. The hesitancy and avoidance appeared to be a fear response, a fear of getting something wrong, of 'saying the wrong thing', which connects to the stigma surrounding mental illness and death and dying as well as the lack of confidence felt by clinical staff highlighted in Chapter 2 (Contextual Background).

5.2.2 Sub-theme 2: Poor access to services

All of the participants described a lack of understanding of what PEOLC services provide and when they can be accessed, both by themselves and by the healthcare professionals supporting them in mental health services and primary care. This varied depending on diagnosis with understanding of the possible need for PEOLC being greater in people diagnosed with cancer. Understanding of the availability of PEOLC for patients with other conditions was extremely limited. Patient and carer participants described not really knowing what could be accessed and when it could be accessed.

> *'I didn't even think of Marie Curie nurses for end of life for it [neurological condition], because you always associate cancer with Marie Curie, you don't think of it' Bridget 1006-1008*

Both patients and carers felt that there was a lack of understanding of PEOLC services in mental health clinicians which supports the findings of the clinician study carried out in 2016 (Jerwood 2016) but also in the physical health teams they were being treated by for their physical health conditions.

In response to a question about whether having access to someone who understands PEOLC would be helpful, Jane stated;

> *'it would because then I could bring it up [with Mum] because actually I don't know what support is out there, it would be helpful for us to know, a little bit, you know, what we can do is this…and even if it isn't for now, so we know when we do need it' Jane 564-567*

This lack of knowledge amongst participants, but more significantly by clinical staff, led either to no referral for PEOLC being made or to late referral. One carer, Bridget, described the negative impact of late referral to hospice services and the financial and emotional impact on her family;

> *'they literally came in the last weeks because we were paying for carers…. we went through the paperwork for funding and X [CNS] said "you should have that [support overnight], that should be paid for" ….and then because someone was sitting with my Dad…we could actually get some sleep. And I think my Mum actually got a good night's sleep the first night that somebody was in, because we were all just emotionally exhausted…….in the last few weeks we had more input from the district nurses, the CNS's and everybody from the hospice, everybody. They were visiting my Mum [carer] on a weekly basis, and I could phone them if I had any concerns about Dad…and we had the hospice at home team who were fantastic' Bridget 555-569*

All participants had different experiences of accessing PEOLC. It was apparent throughout the interviews that there is no care pathway for people in the mental health system who have a terminal illness to access PEOLC services. Some participants accessed community palliative care as a result of having a particular condition, for example, one participant had been the carer for her partner who had a progressive neurological condition which has a specific multi-disciplinary team who look after anyone diagnosed with this specific condition. As this diagnosis is always incurable, this team have some knowledge of palliative care pathways, so accessing PEOLC was more straightforward and clinicians were less hesitant to start conversations about referral. Only one patient participant had accessed hospice care.

None of the patient participants interviewed had been referred to hospice or specialist palliative care by their care co-ordinator at the mental health trust. One patient participant had been referred by a supported housing worker. One carer had looked after her father who had been referred to community palliative care delivered by a hospice in the final

stages of his illness. The husband of one carer, only received end of life care once in a care home. Four patient participants had received some elements of PEOLC from different healthcare professionals which centred on advance care planning and ensuring resuscitation orders, wills and other administrative affairs had been discussed. All the patient participants who were interviewed described a lack of discussion with their care co-ordinators about their PEOLC needs and a lack of referral to palliative care teams in the community, hospital or hospice. Jordan reflected on his experiences;

> *'No-one, not one person on the mental health side has sat down with me and asked what I want. No one has ever contacted the lung team. Not even for my review, I don't get it' Jordan 660-664*

All the participants interviewed felt that they did not know or understand the range of services which PEOLC provided. When they had found out it had been through chance rather than through planned intervention. This was particularly the case regarding day hospice, hospice at home provision, respite and community support. This is illustrated by one patient participant, John;

> *'I didn't know they did a day centre or respite. It's been a lifeline for me as I have no family or friends really, just my neighbour, here I am part of the group just like everyone else' John 741-748*

For the one patient and one carer who accessed PEOLC care it was a positive experience. Negative experiences centred around the absence of referral or access to PEOLC rather than being treated badly within it. Experiences of mental health and general healthcare professionals providing PEOLC information were all negative. Patients and carers were realistic about their expectations about how much each specialist would know about other specialisms but identified a need for better partnership working between specialisms.

5.2.3 Sub-theme 3: Avoiding conversations

The third sub-theme centred on the avoidance of important conversations which participants experienced that led to poor care experiences. Participants felt clinical staff avoided talking about certain topics with them which led to poorer levels of care. In addition, avoidance of some topics such as risk, led to a cautious, hesitant risk-averse approach to patient care and is detailed in this sub-theme. The ability to make decisions

and plan their care was another issue where patient participants felt they wanted involvement in care but where clinical staff avoided conversations with them.

Perceptions that people with SMI cannot engage in end of life care planning and specifically advanced care planning (ACP) were felt by the patient participants interviewed. All of the participants interviewed expressed a clear desire to engage with professionals about their care, their care needs and expectations about the end of their lives. All patient participants clearly stated their ability to engage and their views.

> *'I'd feel better if they took notice of what I had to say, I know myself well now at my age [early 50's] and I know my triggers. I can make decisions, I know what I want to happen to me, and I know how I'd want to be looked after, but they just assume I don't want to, that it would be upsetting…' Stephen 669-673*

Some participants also highlighted how important it was to have support in thinking through the issues and not to be left alone to think about care choices. Jordan has a terminal lung condition, a history of psychosis and a diagnosis of personality disorder. He is 23 years old. He describes the impact of being given a booklet about end of life care planning to complete alone;

> *'it's a bit of a shock you know. You're sitting there, and you don't want to fill it in because you feel like you are signing away your life, you know what I mean? You don't want to think about that when you're 23. You want to be thinking about going out, trying to pull a beautiful girl or you know, going away with your mates on holiday' Jordan 987-991*

Additionally, the patient participants interviewed made very limited reference to risk, in contrast to clinician focused studies in the published literature, which focus on risk heavily (Jerwood 2016; Mental Health Foundation 2008; Woods et al. 2008). Patients felt that they posed very little risk to others. Much of the concern about risk relates to issues highlighted in Theme 1 Stigma and Prejudice. Clinicians concerns about triggering a decline in mental health when talking about PEOLC needs were not shared by the participants interviewed. Patient participants felt that clinicians in all settings were too cautious about talking about mental health, death and dying. Language such as 'treading on eggshells' and 'stepping back' were used repeatedly in the interview data.

> *'there is prejudice when you tell somebody "oh I've got problems with my mental health" you know, they sort of take a defensive step back' John 618-620*

Patient participants felt that care could be improved by focusing less on assumptions of risk and more on talking to patients directly about their mental and physical health, PEOLC needs and addressing these issues earlier on in the care journey. This may include a discussion with a patient about whether their risk increases if they become unwell and what this may look like. Colin commented;

> *'I've got a history of self-harm and trying to end my life twice, more than ten years ago, but I have no history of ever being an issue or danger to anyone else' Colin 619-620*

> *'what I'd like to do…is for me to offer that information if it's relevant, as in "I may behave this way if I am extremely anxious or depressed"' Colin 626-628*

Avoidance of open discussions with patient participants also impacted upon practical issues such as information sharing between agencies. Opinions surrounding the sharing of information initially seemed to be split into two opposing views. On the one hand, patients and carers wanted to maintain a degree of separation between services, particularly in regard to mental health history. Two participants talked at length about wanting to have a choice about what information was shared about their mental health and preferred to share that information themselves when they were ready. This position was informed by previous experiences of prejudice and discrimination which patient participants had experienced in relation to their mental health needs.

Conversely, three patient participants talked about the frustration of a lack of information sharing and felt very strongly that their care had been compromised because mental and physical health services were so separate and communication and information sharing between the two was so poor. Jordan and Lorna commented;

> *'I'd love just one system where it's all in one place. You know, you'd have all their email addresses. So, if they had questions, they could all email each other. Just some way of…you know, because you're thinking, your mind and your body, it's all you. It's you. They're not separate parts' Jordan 1146-1149*

> *'it could be quite important for them to know, to get medication right or whatever…and like get to know you before you go in [to hospice]' Lorna 485-486*

The hesitancy and avoidance that participants identified and patients and carers experienced with regard to both risk issues and information sharing relates to the lack of confidence in clinical staff to approach these issues. With issues such as those regarding advanced care planning, communication of diagnosis and involving patients in their own care, it is the hesitancy and avoidance of having the conversations that leads to patients feeling ignored and uninvolved.

This overarching theme highlights the lack of confidence which clinical staff appeared to have when approaching care planning and delivering care to the participants and their carers. This led to a hesitancy and avoidance of discussions and conversations about patient's PEOLC needs that led to multiple experiences of poor care. It links to the issues identified in Theme 1 Stigma and Prejudice. The fear of mental illness and the fear of dying which underpins stigma in clinical staff links to the hesitancy and avoidance which participants experienced as 'treading on eggshells' around them. Hesitating and avoiding important conversations about diagnosis and prognosis, care needs and end of life care preferences led to poor experiences and poor access to services amongst the participants interviewed.

5.3 Overarching Theme 3 – Collaborators in Care - The 'ignored experts'

The third conceptual theme concerns carers experiences of care and collaboration with healthcare professionals and services. The role of carer of a person with SMI and a terminal condition is complex. The degree to which members of the informal care network (ICN) were involved on a day-to-day basis varied. For some participants, their ICN was made up from lots of people who were more marginally involved, like neighbours or other service users, members of support groups or churches. However, some participants had close family members who were their primary carer or were the primary carer for someone in their immediate family. Participants described both a great depth and breadth to the role, characterised often by a long period of caring for the person's mental health needs prior to their terminal diagnosis.

Three carers were interviewed. Two were carers of people who had already died and one was a carer for a patient participant in the study. The interviews with carers were rich stories of contradiction. On the one hand carers were expected to be experts, full-time advocates, expert in conditions and treatment and able to provide intimate and personal care. On the other hand, the carers who took part described feeling ignored and dismissed by clinicians and service providers. Communication with carers was poor, sometimes they were identified as 'part of the problem', which they felt was particular to caring for someone with a mental health condition. They described being expected to fill in any gaps, whilst receiving little or no support or information.

> *'The GP should be the central point but once other agencies are involved they aren't really – they are supportive but they don't co-ordinate anything, you have to do that' Bridget 566-567*

The title of this theme reflects this paradox, Collaborators in Care - The 'ignored experts'. Three sub-themes were identified within the overarching theme 1) Experience of the caring role 2) Ignoring my needs and 3) The impact of caring.

5.3.1 Sub-theme 1: Experience of the caring role

The role of carers varied from practical and day to day support to emotional and psychological support. Carers described the practical aspects of the role as physically draining. All three carers referred to 'putting their lives on hold' and albeit willingly, they all referred to the negative impact this had upon their well-being. Physical tasks included sleeping overnight with the person, personal and physical care, administering medication, lifting, attending appointments, supporting with household tasks. Lorna and Julie reflected;

> *'yes, and my daughter gives me my injections every week' Lorna270-271*

> *'it does take over your life and it fills your time in a different way, he was always first before anything else' Julie 295-296*

All carers interviewed stated that they wanted to take on this role, but that they lacked support and services to enable them to do the role effectively.

> *'so then we had to get a different care agency, but that's purely through our own research. There was nobody to help us with that' Bridget 113-114*

However, by far a greater role was the role of the carer as advocate and 'translator' between services and the patient. This seemed to be particularly important for this patient group who described difficulties with communicating with professionals and engaging with new services. Carer participants described needing tenacity and determination, especially when trying to access support services. Bridget stated;

> *'purely through my tenacity…everything he needed, like day release or day support, for mum to give some respite, I had to fight for….it took about four months to get agreement for that to happen. And then he attended for about six weeks and then he couldn't attend any more, that was about two years into his condition' Bridget 104-109*

Carer participants also described a large aspect of their role being in helping the person they cared for understand the diagnosis and treatment they were being offered, alleviating anxiety and distress this sometimes caused.

> *'we had to help her understand what it meant, how having a stoma might help her quality of life, she was so frightened' Jane 116-118*

Carer participants felt it had been necessary for them to become very informed about the conditions, treatment and support the person they were caring for may experience or be able to access. None of the carers interviewed felt confident that clinical services were able to meet the needs of the person they cared for as Bridget and Julie described;

> *'it was one hospital in particular that I won't mention and we filled in the 'this is me' type form and said he was vegetarian…and we went in and he was eating a cottage pie…when we asked the staff they said 'well he ate it'…and we were like 'he ate it because you put it in front of him and he doesn't know he can ask for anything different' Bridget 1153-1157*

> *'because his speech wasn't very clear they just didn't even try to communicate, it was like 'oh well, it's a mental health thing so we don't have to try' was how the staff viewed it, 'we just do the physical care and that's it' Julie 343-347*

One carer had taken a University module in the condition her father has to enable her to better support his needs. Two carers were adults caring for one parent and described the reality of needing to care for the other parent as they coped with the impact their partner's diagnosis and illnesses had on them. Bridget describes supporting her mother to cope with her father's illness;

> *'I mean I've obviously been proactive in my research as what to expect, purely to protect my Mum, because she doesn't cope well with stressful situations…. but I didn't realise what an end of life package was about until I'd done the course at Uni' Bridget 374-380*

All three carers felt they were holding a role similar to a care co-ordinator and a large part of their role was to liaise and keep all the agencies involved informed. One carer participants' illustrated this role;

> *'there are so many people involved, it's a full-time job…no -one speaks to anyone else and you are left to do all that' Julie 455-456*

The role of the carers was complex and far-reaching and had impacted significantly upon the lives of the carer participants interviewed. All were keen to emphasise that they wanted to care but that the impact on their own health and well-being, as discussed in Sub-theme 3, had been great and despite becoming well-informed, they too had support needs which were often not met.

5.3.2 Sub-theme 2 - Ignoring my needs

Carers' experience of caring and the support they received to be a carer was very mixed. One carer, who was caring for her husband who had a terminal neurological condition, felt she had been supported well by the multi-disciplinary team (condition-specific) within the mental health trust. This is a team which only exists for a specific condition, so other carers hadn't had access to the same type of team. Julie reflected positively on the support she received;

> *'there's an OT, a dietician, a speech and language therapist, the research fellow and the professor…he's an absolute flippin' encyclopaedia Britannica…they are an absolutely magnificent team…. carers couldn't do the job they do without that team behind them' Julie 170-175*

However, her experience of being a carer once her husband went into a care home was, by contrast, very negative. She felt marginalised from decision-making and that her expertise was ignored;

> *'you know when you've looked after someone you know what their limitations are, what they can and can't do' Julie 653-654*

> *'….and when he went to the care home, the GP would change…I wasn't told that and that was the decision taken away from myself and X…I had no idea once he met the criteria for continuing healthcare we would lose his social worker. That should be made, people should be made aware of that' Julie 37-38*

Patient participants also described experiencing negative treatment of carers and felt they could be side-lined, marginalised or even blamed for some of the difficulties the patient with SMI was experiencing. Colin reflected on how he observed carers being treated;

> *'they can be dismissed or not taken with any kind of authority by professional people. They have a similar experience to me. I've had them in meetings with me and they've been overlooked, dismissed or excluded and I've wanted them included…. they can have, very much, a similar experience to the patient' Colin 987-996*

Both patients and carers found the tension between being expected to be experts taking on full-time caring roles and being ignored and stigmatised very difficult, but also non-sensical. Carers felt they had useful skills and knowledge to support professionals in the care of the person with SMI, but that the partnership between carers and professionals was inadequate.

All three carers highlighted the unmet support needs they experienced. Accessing night cover and respite for people with more serious illness was a key area which carers mentioned that they were not aware of, or didn't realise could be provided by PEOLC services. Their perception was that this would be something which had to be privately funded. All three carers were not provided with any information about PEOLC services or how to access them until just before the person they cared for was dying.

> *'no, no-one has mentioned palliative care…even when they said the treatment wasn't working…we haven't had any information about a*

> *hospice certainly…I thought that was just for the last bit really to be honest' Jane 998-990*

All three felt that earlier referral to palliative care would be helpful. Bridget commented;

> *'It did cost us a bit to have night sits as well. But again, we didn't know that Marie Curie could provide that service until quite late on in…'Bridget 473-475*

Two carers discussed the gap between support received at the point of the diagnosis of the terminal condition and the last weeks of life. The carers described a need for ongoing support from services which understood the specific conditions the patient was experiencing. They felt they needed someone who could keep regular contact and advise them of what services were available as the patient's condition deteriorated. Carers highlighted the need for care co-ordination between agencies and felt the mental health trust care co-ordination and GP support were lacking. They were sympathetic to the pressures experienced by these professionals but highlighted the need for better support for them in their roles as day to day carers of people with SMI and terminal conditions.

The two carers who had already been bereaved described the impact of bereavement and lack of support afterwards on them. Both had spent much of their time in the caring role, so felt the additional loss of purpose as well as the loss of their spouse or parent.

> *'Our life was on hold for five years, and my Mum's, but now we don't have that to do' Bridget 908-909*

> *'I wouldn't say I am living, I think I'm sort of functioning. I don't think existing is the right word because I am doing a bit more than existing……caring is a role, not a job, but it takes over your life and fills your time in a different way, he was always first before anything else' Julie 288-295*

One carer had accessed bereavement support through a voluntary sector organisation however, the other carer had received no bereavement support at all. The lack of support for carers contributed to poor experiences of care for their family member as it left the carer with responsibility for accessing appropriate treatment, care and support, which not all carers have knowledge or ability to do. As highlighted in Theme 1 Stigma and Prejudice, many people with SMI have limited or fractured family and social support networks and some participants highlighted that often their carers have mental and

physical health needs of their own. To carry out the caring role, carers require greater support throughout the caring journey.

Poor access to services not only impacted upon the patient as highlighted in Theme 2 Hesitancy and Avoidance, but also on the carer. Referral to PEOLC, and particularly hospice care, often opens up access to support services for carers as well as patients including bereavement support which most mental health trusts don't routinely provide, so even if carers are linked to mental health carer support, they may not get their needs met once the person they are caring for develops a terminal condition.

5.3.3 Sub-theme 3: The impact of caring

The carer participants interviewed described a big impact on their own health and well-being. This included physical impact as well as emotional and psychological. Being a primary carer had led some carers to made radical changes to their lives such as giving up work or moving in with their relative. Julie talked about the impact of being a carer on her working life;

> *'well I worked up until 2014……and then this one Sunday X was getting out of his chair and he fell and cut his head open…and that's when I packed up work. I thought I can't do this because if he falls and the kids are at home anything could happen….so I packed up work and worked at home doing ironing for people' Julie 193-203*

Where one or two family members undertook the caring role, they expressed concerns for each other. Two participants described postponing surgery because of their caring role;

> *'and he is going through discussions with a consultant at the moment, about an operation, and it's quite a big operation, and we are thinking of the recovery for him, and he says, 'I don't think I can have it done because of your Mom' Jane 750-753*

> *'it would take a lot of persuading really for my Dad to consider having some form of treatment for his own health' Jane 756-759*

> *'they said, we can't do this surgery [shoulder injury repair] until you aren't caring for X. Because it costs money to put somebody right….' Julie 693-696*

All three carers described the emotional strain of caring but also the guilt of using respite services (if they were available). All the carers interviewed referred to the strain of trying to manage the physical and emotional impact on them and the other family members involved. Bridget's experience of lack of availability of respite illustrates this strain;

> *'when we were at home we had baby monitor alarms. I had one in my house and my mum had one in the bedroom, because my Dad slept downstairs. So I don't feel like any of us slept for five years because we were always sleeping with an ear open.' Bridget 537-541*

> *'I did have to put him in respite when my step-daughter got married in Cyprus. And that was the worst week of my life, let alone his, because I felt I'd abandoned him by putting him in……. they could go together…… but because he was agitated she never got a break at all. So that was probably the worst thing I ever did.' Bridget 453-462*

The issue of time was highlighted by all three carers and some patients. The difficulty of attending carer support sessions or groups was highlighted when inadequate respite care is still a problematic issue. Carers felt they should prioritise the patient over their own well-being. Lorna reflected on the issue of support for her carers;

> *'No, no, no they don't get support. I get support from them but they don't get support' Lorna 633-634*

Participants reflected that caring for someone with complex mental and physical health issues is a difficult and all-consuming role. Whilst none of the carers interviewed wanted to stop, or not to have taken on this role, they all reflected upon the negative impact of being a carer and the lack of support available to carers. This was exacerbated, participants felt, by caring both for someone with a mental health diagnosis and someone with a terminal condition. The complex needs which SMI brings were exacerbated by the stigma which carers, as a well as patients, experienced which was reported in Overarching Theme 1 Stigma and Prejudice – 'See me not my diagnosis'. The pressure on carers to be 'experts' was deeply felt and made difficult by then being excluded from care planning discussions and feeling unsupported by professionals. One carer, Julie, explained how her partner's GP changed without her knowledge;

> *'I mean I had lasting power of attorney over his health and his care and all that and they didn't even consult us, it was just like, now he is here*

> *this is his new GP….which meant we lost other support we had through the practice…it just seemed like "he is in our care now and we know how to look after him best" but they didn't even know what he liked to eat or watch on TV…' Julie 373-379*

This overarching theme highlights the difficult and complex situations which the carer participants found themselves in when the person they were caring for became terminally ill. Participants had given up their careers, experienced a decline in their physical health and experienced a lack of support, and at times respect, from clinical services. In addition, they felt the expertise and knowledge they developed through taking on the caring role was dismissed and ignored when it came to planning and delivering care to their family member. Much of the discrimination they experienced was similar to that experienced by the patient participants and related to perceptions of mental illness and terminal illness held by clinicians and health services.

5.4 Overarching Theme 4 – Connections 'Leaning in, not stepping back'

The fourth overarching theme concerns participants' experiences and feelings about the relationship with clinicians and services and the impact of this on their PEOLC needs. It includes three sub-themes 1) Disconnecting and Abandonment – 'stepping back', 2) Attuning – 'leaning in' and 3) Making Connections – 'working together'. The overarching theme encompasses some positive but mostly negative experiences of care.

This is best summarised again by John who described his desire for professionals to 'lean in';

> *'I just needed them to lean in, when I most needed them to lean in, they stepped back' John 612-614*

Participants' experience of disconnection and connection, and professionals' ability to attune to their needs ranged across many aspects of their care. The ability of services to work in partnership with other organisations or departments, communication between clinicians and between clinicians, patients and carers were all areas where participants felt a chasm or void that contributed to their overall poor healthcare experience. The impact of the experiences captured in the first three overarching themes link to the experiences shared by patients which contributed to this overarching theme. Fear, stigma and prejudice underpin this theme, as does the lack of confidence of clinical staff

identified in Theme 2 Hesitancy and Avoidance. The concept of the theme centres upon the difference between feeling disconnection and abandonment and feeling connection and a sense of attunement with clinicians and services. The ability of clinical staff to lean in and get alongside participants was what made the difference between positive and negative experiences of care. Positive experiences were minimal in the participants interviewed but where positive experiences happened they were characterised by the quality of relationship between the patient, carer and clinician.

5.4.1 Sub-theme 1 Disconnecting and Abandonment – 'stepping back'

Four patient participant's experience of how mental health services responded to their terminal diagnosis (and their physical ill health generally) was that of being abandoned. Lorna described how she was discharged from secondary mental health care back to her GP without being informed. A carer participant, Bridget, described also a similar experience;

> *'they just wrote to the GP and said I was being discharged from the CMHT…after thirty years, thirty years…. I needed help even more once I knew about the cancer, not less' Lorna 542-546*

> *'so in a way it was a discharge from the service…once the medication stopped, we had no contact with the team. It was a case of phone us if you need us' Bridget 78-84*

Jordan described receiving a letter about his care changing whilst in hospital, rather than in face to face contact with his care co-ordinator;

> *'well I was in x hospital when I found out I wasn't going to x service anymore, they sent me a letter saying I was being moved before they even told me. So I got a letter, I was reading it, saying "you've been transferred" and I was really confused, and I felt really, sort of like, they're pushing me away like everyone else does' Jordan 458-462*

None of the patients interviewed had been provided with any information by any of the professionals involved in their mental health care about palliative or end of life care services or been referred. One patient participant *had* been referred to hospice care but by a housing support worker. None of the patients interviewed described healthcare professionals, taking a holistic approach by engaging them in conversation about both their mental and physical healthcare needs. As highlighted in Theme 1 Stigma and

Prejudice, healthcare staff in acute and physical healthcare settings also disconnect from patients, but rather than this being prompted by their terminal diagnosis, it is prompted by a mental health condition being present. Participants sometimes experienced this as stepping back rather than overt prejudice.

John described clinical staff [oncology team] response once they knew he had a diagnosis of schizophrenia;

> *'there is that prejudice when you tell them "Oh I have problems with my mental health" you know, they sort of, they take a defensive step back…. people with mental illness, we haven't got the black death, as soon as you mention mental health people go 'bleurghhhhhhhh' you know, and that is more scary than having a mental illness' John 647-650*

Consistency of care was identified as important for all patient and carer participants. Whilst all participants expressed an understanding of the pressures on services that lead to inconsistencies in care, they all identified this as particularly problematic for people with SMI and terminal conditions. This was particularly relevant in relation to changes in mental health care co-ordinator. Three patient participants had experienced the retirement of a long-term care co-ordinator who had not been replaced with one person, so a long-term relationship had been substituted with multiple clinicians holding the role, or no-one holding the role. Jane reflected on the impact of this loss of relationship on her Mum;

> *'she had a good relationship with him for more than ten years and he retired and she had no-one, she was supposed to be on the team manager's caseload but we have not met him or had any contact from him, they are just under so much pressure but that doesn't help my mum who has fluctuating psychotic symptoms and now is terminally ill' Jane 344-348*

Stephen added;

> *'I don't know him, I don't see him very often and I don't think he knows how it feels to have this condition' Stephen 566-567*

This loss of consistency was felt to be very difficult when a terminal diagnosis was received, and the patient was encountering new services and having to build new

relationships. One carer participant, Jane, described her feelings about how her Mum's contact with the CMHT was handled following her traumatic terminal diagnosis of cancer;

> *'if it was me, if I was a CPN working in a CMHT, I would have been ringing my Mom the following day following her presenting at Duty, and actually seeing how she was, how were her symptoms and I would have done a follow-up call for sure, even a visit…but no, there was none of that and it was like "is anyone coming out to see my mum at all"?' Jane 669-680*

Another aspect of care where participants felt abandoned were when they were introduced to aspects of advanced care planning (ACP). Jordan, who has a long-term terminal lung condition, described being given a booklet by a member of staff in the clinic he attended for his lung condition.

> *'it's not like me and you, you know, we haven't sat down and chatted about what we'd want, how I'd want to approach everything, and all that sort of stuff, but you're given this booklet and they don't help you with it. They just say, "take it home, fill it in and give it back to us" …you're sitting at home and it's like "would you want to be resuscitated?" you get like three options……it's a bit of a shock you know' Jordan 863-872*

ACP is something that would usually be carried out between the patient and the services and clinicians involved in their care, possibly with family members, and includes the completion of more than a set of paperwork. The other issue which arose in discussions about ACP was both carer and patient participants ending up undertaking elements of ACP by themselves. For some participants who were not engaged with PEOLC organisations or services, elements of ACP had been carried out between family member with the help of solicitors.

> *Researcher: 'Has anybody, any professional you have come across talked to you about things like how you'd like to be looked after, or advance care planning?*
>
> *Patient: 'No, nothing at all and I've done ye will myself' Lorna 555-558*

Lorna nominated a carer, Jane, to be interviewed, who answered the same question;

> *'No, no, the only thing that's been said is that if it develops into the next stage…that she will have a matter of weeks because there wouldn't be any treatment… she will be very end stage, and that's well, we will deal with that when it happens, there hasn't been any kind of [pause] no, nothing at all' Jane 444-449*

Julie recalled that she had carried out some ACP aspects with her husband and a solicitor in response to a healthcare professional saying her husband would need to be tube fed soon. Julie knew this was not her husband's wishes and so it prompted some planning between the couple;

> *'she said about the PEG feed and I said he doesn't want that, so we had the lasting power of attorneys drawn up, new wills and an advance directive' Julie 466-468*

These four participants all reported poor experiences, not positive examples of how advanced care planning should be carried out. When patients and carers have to resort to putting their own plans in place in isolation, it could be counter-productive, as the lack of involvement of organisations and healthcare professionals means it may be less likely that these plans can be implemented when the time comes. The disconnection and abandonment which participants felt when in contact with different parts of the healthcare system was profound, and more extensive than solely in mental health or PEOLC services. There were few examples of where participants felt listened to and heard, and where clinical staff were alongside them in their care and in decision-making. This was the desired approach from patients and the second sub-theme explores the concept of attunement, or as one participant described it 'leaning in' to provide a good healthcare experience.

5.4.2 Sub-theme 2 Attuning – 'leaning in'

This sub-theme focuses on experiences participants had where they felt services or clinicians were attuned to their needs. John was the only participant who accessed hospice care. He has a long history of schizophrenia and found engaging with mental health and other health services difficult. He had no family support and only practical support from some neighbours. He did not have anyone he wanted to put forward for

interview as part of his informal care network but described very positive treatment by the hospice in regard to understanding his mental health needs;

> *'Oh it's been fantastic it really has…they have got to know me not the illness' John 584-585*

John's experience was of being treated as John, not the 'schizophrenic patient' or the one who looked different to other people in the day hospice. John was initially resistant to thinking about any aspect of care planning for the end of his life, however, after attending day hospice for some months this changed;

> *'I mentioned it [ACP] in passing to him [Day Hospice Nurse] and half an hour later he came back with a big pile of leaflets….it wasn't "there you are, plan your own funeral" he sat down and talked me through it and said there's nothing to be worried about, you can do this quite easily you know…' John 478-486*

He went on to describe how ACP had been approached in stages;

> *'I think when I first started coming to the hospice I filled the form in and it asked me where I'd you know, where I'd like to die, at home, at the hospice, in the hospital, you know….and I'd mentioned it [ACP] in passing a few weeks before, and then I didn't think anything of it and it's nice to know people are picking up on that…and trying to help. It would have been too much at the start but it's ok now' John 522-525*

John also described the wider benefit of hospice care;

> *'Company. I'm very isolated where I am so company is one of the major things. Urr... the other thing I get is it keeps me grounded. I know it sounds strange but when I walk into day hospice it brings it home to me, yeah, I've got cancer, I'm dying. Whatever. But I am not as bad as some people here……yeah, yeah, it's almost like a family, the group we've got is almost like a big family, so…[pauses] it is, it means a great deal to me actually coming here' John 127-140*

John described himself as someone who does not easily trust or 'let people in' but had found the gentle approach in the hospice helpful in engaging him in the wider hospice offer.

> *'I came to see the art therapist first, and he introduced me to a nurse after a few weeks. Then I came to visit day hospice and they explained I could come for respite too if I needed it…they helped me when I had to re-home the dog too. I think I'd like to be here at the end you know…which I never would have thought of before' John 99-126*

Another patient participant, Stephen, had received some support with regard to his benefits and housing as part of a visit by a palliative care clinical nurse specialist to a voluntary sector project he attended. This participant has multiple physical health conditions including brain damage and alcoholic liver disease and a thirty-year history of a range of complex mental health conditions.

> *'Life has got a bit easier financially, I've been awarded the highest rate of all the mobility stuff, living allowance and all that, so I'm alright for money…. the nurse [CNS] helped me to do it…and I have my flat all sorted now so that has made me much less worried about how I'll be as I get more ill' Stephen 656-663*

For these two participants it was not the setting in which the advance care planning took place that made the difference in these two experiences, it was the approaches of the members of clinical staff. It was their ability to have the right conversation at the right time. Clinicians have expressed concern about carrying out ACP with people with SMI (Jerwood et al. 2018) however, people with SMI have expressed a desire, and the ability, to be involved in the planning of their care (Foti et al. 2005; Sweers et al. 2013). Patients who engaged in some planning, whether it was supported or on their own, described the relief of knowing that they had been able to discuss how they would like to be cared for and to make plans. John stated;

> *'it hasn't been distressing at all, it's been really helpful…. I've dealt with it and it's out of the way and I don't have to worry any more. It took the worry out of it' John 568-569*

Flexibility of approach was felt to be important by participants. Fluctuating mental and physical well-being led participants to require clinical staff in all settings to adopt a flexible approach. Participants commented upon the need for flexibility with appointments, location of appointments, time of day, cancellations at short notice and needing services to adapt to meet their needs as their illnesses progressed. Patients and carers referred

to the need for flexibility in different ways. Bridget highlighted the need for flexibility with timing for appointments;

> *'I suppose what would help is the nurses, district nurses and hospice nurses, having more awareness of mental health and its issues, that you can't expect a 15-minute appointment to be a perfect 15-minute window because it won't be, sometimes it takes time to reassure and explain what's happening before it happens, especially if there are painful or new procedures' Bridget 735-737.*

Where services were attuned to individual needs, participants reported significant benefit to their mental health. Jane described how improved care co-ordination and flexibility within services allowed her mother to have an expediated admission process when she needed IV antibiotics which reduced her mental distress by avoiding a lengthy wait in A and E.

> *'the GP is very good and now she [Mum] does have that support when she's not well….so she has to go into hospital regularly because she is having chemotherapy…and 18 months ago you'd have to ring the GP….then it would be up to 12 hours in A and E and then she'd be admitted and wait another six hours for a bed….where now she can just ring the ward and be admitted straight to the ward which is much better for her mental health' Jane 294-305*

When services are able to respond to individual needs, by listening to patients and carers, it also makes patients less likely to delay seeking treatment. This highlights how some of the delayed diagnosis issues raised in Theme 1 Stigma and Prejudice and Theme 2 Hesitancy and Avoidance can be overcome.

5.4.3 Sub-theme 3: Making connections – 'working together'

This sub-theme concerns issues in partnership working, poor communication between agencies and care co-ordination. People with SMI and long-term physical health conditions come in to contact with multiple different services within the healthcare system, both within the NHS and the voluntary and community sector. Once a patient also has a terminal or life-limiting diagnosis, they will also potentially come into contact with many more healthcare professionals. Patients and carers highlighted multiple issues regarding poor communication between agencies which contributed to the feeling that

clinicians and services are avoidant or 'step back'. Better partnership working across different health care services and between clinicians, patients and families was highlighted by participants as one way that experiences of PEOLC could be significantly improved. In addition, as previous themes have highlighted, people with SMI experience a lack of referral to PEOLC and delays to being diagnosed and accessing treatment which could also be improved by better partnership working.

Carers highlighted the gap between receiving a terminal diagnosis and entering the last few weeks of life. Support was received for some patients at the time of diagnosis and right at the end of life, but there was a significant gap, sometimes of years, between these two events where carer participants felt they needed support, particularly from mental health services. For Bridget this has been a significant gap in care;

> *'I suppose ideally, I know it's probably too much, but a weekly contact, or at a bare minimum, a monthly contact, somebody saying "how's things going?" …because as I say once the nurse finished with him in the January last year, we've had no contact from anybody from there [mental health trust]. And here we are in December, I don't know if I should tell someone he has passed away, I suppose I should…. [pauses] but there's no follow-up….' Bridget 973-982*

This was also echoed by Jordan and Lorna;

> *'just like if there was a service, a co-ordinator where if they have questions, they can communicate, and set up a review meeting or something, it's all separate and you don't know when you can access what, it's all too late' Jordan 1102-1105*

> *'I need someone to check in with me and see if I am ok and then as things progress, they can flag up what's available where cos I don't know, how am I supposed to know, and what's the point of having a care co-ordinator if they don't co-ordinate anything? Lorna 589-595*

In addition to a perceived lack of knowledge about PEOLC in physical health clinicians, particularly in mental health services, participants highlighted the issue of care co-ordination and the need for greater connection between services and partnership between patients, carers and services.

The carers interviewed described having to be responsible for communication between agencies. At times they felt that communication with them as carers was inadequate as described in Theme 3. For patient participants without close carers, there was a lack of communication between services and the patient. None of the patients interviewed had experienced a case conference, or review or multi-agency meeting regarding their care and they described a disconnection between the agencies looking after their mental health care and those looking after their physical health care.

The communication between mental health services and PEOLC services was not only inadequate with regards to referrals into PEOLC, but for the patient who was accessing PEOLC, there was no communication that the patient was aware of. In response to a question about whether the hospice and mental health team had been in contact or met with the patient together John said;

> *'I don't know whether they have or not, no-one here [hospice] seems to know about my mental health unless I have told them, it's not something I have been part of if they have' John 229-233*

One of the areas where patient participants felt care co-ordination was important was in relation to medication. Whilst a patient's GP retains a role in being the consistent service involved, many patients with SMI do not have regular contact with their GP and their complex medication regimes are monitored by the CMHT. When their physical health needs become more complex, and when other clinical staff from acute services and PEOLC teams become involved, there is a need for communication regarding medication review. The problems with lack of care co-ordination in this regard were highlighted by Colin in relation to being prescribed a new medication he was concerned about;

> *'so there was all that going on…they were poles apart and nobody would get together and talk, really. The GP was doing one thing and the psychiatrist was doing another…and I was seeing another specialist as well and so…things were…sometimes, done to me or for me, but I didn't feel included in any of it at all' Colin 393-400*

Jane described the impact of a lack of care co-ordination and poor communication on clinician's understanding of the patient's mental and physical health and how they impact on each other;

> *'sadly there have been big gaps. You know, I think their expectations of Mom "well can you come to the clinic today or see the GP?" [in response to a decline in mental health] Well my Mom isn't physically able to and they say "well as long as you get out and about" and "make sure you go out every day" and it's like, my Mom isn't fit enough to go out, you know and I don't think they understand the impacts of the physical health side of things on Mom, her ability to do things, physically do things' Jane 393-400*

Jane felt the lack of consistency was also related to being a dying patient;

> *'and I think she feels, and my Dad does, well they feel really abandoned, in her head she thinks it's because she has had a stoma and she is dying anyway so they're [CMHT] not that bothered' Jane 427-429*

Where consistent care was provided, and relationships could be developed, it was beneficial for patients in terms of reduced challenging behaviours and in building trust to enable difficult conversations to take place. Bridget's experience was more consistent and positive;

> *'then the nursing team was always the same nurses, it was the same faces we saw every week. And that was helpful for him because he recognised that they were familiar faces….so he built rapport' Bridget 302-306*

Three patients also described the importance of building rapport and relationships with new services and how that would enable better care to be provided. This is illustrated by Lorna thinking about building relationships with a hospice;

> *'but actually meeting the hospice where you'd like to be cared for, I mean also we are isolated within ourselves when we have a terminal illness AND a mental health condition, but yes, where you'll be cared for…letting them get to know you so they know how to care for you' Lorna 518-521*

The problems of poor communication and co-ordination between services were particularly highlighted when patients were admitted to acute hospital care, often through the Accident and Emergency department (A+E). Both patients and carers described this

experience as particularly difficult and distressing. Admissions placed a significant burden on carers who all felt that acute settings were unable to cope with the needs of the person they were caring for. Julie and Bridget had both had negative experiences in A+E with their relatives;

> *'I mean I stayed with him the whole time he was there because you couldn't leave him on his own then it was just, they couldn't have coped, there wasn't enough staff and he wouldn't have coped with it either you know' Julie 633-637*

> *'it was traumatic to say the least, because I think I was stressed because I knew my dad would end up getting stressed because he couldn't sit still for long. And then when he started to get agitated he'd get aggressive' Bridget 161-165*

There was recognition in carer and patient participants that acute staff were not adequately trained to support people with complex mental health needs and that staffing levels made it difficult for staff to spend sufficient time with patients to meet their needs, however, it was clear that acute admissions were very difficult for the patient participants.

> *'well he'd actually been in hospital with pneumonia. And he wasn't looked after at all well. They just didn't understand how to cope with his agitation because he was out of his family environment' Bridget 1134-1136*

The lack of care co-ordination and lack of involvement of PEOLC services meant that avoidable hospital admissions and presentations to A+E were common in the participants experience.

This sub-theme has highlighted the need for better communication and co-ordination of care, for better partnership working between agencies, and for better communication with, and involvement of patients and their families. Participants consistently identified that their care fell between the gaps between services, in addition to already experiencing stigma, prejudice and avoidant care. Making connections and working in partnership is an essential part of providing better care and meeting the specific needs of people with SMI in PEOLC.

5.5 Summary

The four overarching themes developed in the analysis of the participant interview data are distinct but interrelated and form a conceptual framework defining the current multiple poor experiences of people with SMI and terminal conditions and their carers as experienced by this cohort of participants. The stigma and prejudice experienced by both the patient and carer participants was consistent and profound. In all areas of healthcare, this patient group are disadvantaged by both their mental health status and their identity as a dying patient. Past experiences of stigma and prejudice in healthcare informed their current relationships with healthcare services and clinical staff.

The hesitancy and avoidance in clinical staff, identified by participants, particularly when thinking about their experience of being diagnosed, their experience of being referred to or accessing PEOLC services and of trying to be involved in the planning and delivery of their care were extensive. The feeling of 'treading on eggshells' of 'getting it wrong' of potentially de-stabilising a patient were felt by the participants. Conversations which they felt clinicians found difficult, were conversations and discussions they wanted to be involved in. Participants suggested that clinical staff in non-mental health settings needed better understanding of mental health issues and conditions, and vice versa, that mental health staff needed to feel more confident in talking about issues surrounding death and dying. In addition, they felt that clinical staff needed better awareness of services and support available and how and when to refer patients. However, participants also reflected that they did not expect clinicians to know about every specialism, but that they would need better skills in talking and discussing individual needs with patients and carers.

Carers were consistently over-burdened and experienced healthcare staff and services as expecting them to have a degree of expertise whilst consistently feeling ignored or excluded from care planning and discussions regarding their family member. The breadth, depth and complexity of the caring role was apparent throughout the carer participant interviews. It was evident that the lack of a care network of the majority of the patient participants was acute.

The overwhelming feeling of the participants, captured by one participant as that of services stepping back when he needed them to lean in, was conceptualised as disconnecting and attuning. Few positive care experiences were identified where clinicians attuned to patients and carers individual needs. Negative experiences

occurred where clinicians disconnected or failed to connect with patients. The importance of attuning to patients and making connections were apparent throughout the thematic analysis.

Overall participants in this study had multiple experiences of poor care. The themes developed from the patient and carer interviews of ‘Stigma and Prejudice’, ‘Hesitancy and Avoidance’, ‘Collaborators in Care’ and ‘Connections’ were used to inform the design of the next stage of the co-design process the workshops, as well as informing the conclusions and recommendations for clinical practice presented in Chapter 8 (Implications, Recommendations and Conclusions).

This chapter has presented the findings of the first stage of the co-design process, the patient and carer interviews. The next chapter presents the findings of the workshop stages of the co-design process.

Chapter 6 Co-Design Findings - Workshops

The previous chapter presented a thematic analysis of the patient and carer interviews and identified overarching and sub-themes. These themes informed the design of the second stage of the co-design process, the workshops. This chapter reports on the findings of the workshop stages of the co-design process. In a traditional qualitative study, the data would be collected, analysed and then findings or results reported. In co-design, there are iterative rounds of data collection which inform the design and results of subsequent rounds (see Figures 2 and 3). The participatory origins of co-design allow the participants to collaborate with researchers to develop the research findings and subsequent questions or tasks.

The chapter is divided into stages to reflect each group of findings. Some reference to the analysis of the data is included, where it adds helpful illumination to the approach to the subsequent stage of data collection. The detailed process of data analysis has been previously described in Section 4.10 (Data Analysis).

6.1 Co-Design Participants

Participants were recruited to the workshop stage in three cohorts (see Table 13 Co-design participants). The first two cohorts were recruited from the West Midlands. However, the third cohort was recruited from a neighbouring region. This was an amendment to the original research design, but in response to a second mental health trust and hospice from a neighbouring region wanting to become involved in the study. It was felt by the researcher and supervisory team that this would add a wider cohort of participants and broaden the geographical reach of the study, so an amendment to the protocol was submitted to the NHS REC, HRA, University and the new organisation's research department for approval. This was quickly granted as the amendment posed no additional risk to participants (see Appendix 3).

Each cohort participated in two workshops. The first round of workshops was held with each cohort, the data subject to initial analysis and presented back to the second round of workshops, as part of the co-design process outlined in Chapter 4 (Methodology). A summary of attendee's roles is included in Table 13).

Table 13 Co-design participants

	Cohort 1	Cohort 2	Cohort 3
Workshop 1	1. Art Psychotherapist – Adult MHT Community 2. Peer Support Worker and Service User – MHT 3. End of Life Care Facilitator – Acute Trust 4. Outpatient Palliative Care Nurse – Acute Trust	1. Specialist Palliative Care Consultant 2. Occupational Therapist – Neuro MH 3. Clinical Psychologist – Health Psychology (Cancer) 4. Mental Health Student Nurse 5. Mental Health Student Nurse 6. Service User 7. Carer 8. Carer Support Worker – MHT 9. Community Nurse Specialist – Hospice 10. Head of Community Nursing - Hospice 11.	1. Clinical Psychologist – Cancer and Palliative Care 2. Trainee Clinical Psychologist – MHT 3. Consultant in Palliative Care – Hospice 4. Consultant Psychiatrist – MHT 5. Matron – OPMH In-patient 6. Head of Clinical Services – Hospice 7. Practice Educator – Hospice 8. Speciality Doctor – Old Age Psychiatry 9. Charge Nurse – Older Age MH 10. Psychiatrist Older Age MH 11. Mental Health Nurse 12. Community Occupational Therapist – MH 13. Clinical Nurse Specialist Palliative Care – Acute 14. RMN – MH 15. RMN Older People's MH 16. RMN – Older People's MH
Workshop 2	1. Clinical Health Psychologist- Hospice and MHT 2. Mental Health Student Nurse 3. Peer Support Worker and Service User – MHT 4. Community Nurse Specialist -- Hospice 5. Art Psychotherapist – Adult MHT Community 6. End of Life Care Facilitator – Acute Trust 7. Outpatient Palliative Care Nurse – Acute Trust 8. Occupational Therapist – Neuro MH 9. Carer Support Worker - MHT 10. Service User 11. Carer 12. Community Nurse Specialist - Hospice		1. Clinical Psychologist – Cancer and Palliative Care 2. Trainee Clinical Psychologist – MHT 3. Consultant in Palliative Care – Hospice 4. Consultant Psychiatrist – MHT 5. Head of Clinical Services – Hospice 6. Practice Educator – Hospice 7. Speciality Doctor – Old Age Psychiatry 8. Charge Nurse – Older Age MH 9. Psychiatrist Older Age MH 10. Mental Health Nurse 11. Community Occupational Therapist – MH 12. Clinical Nurse Specialist Palliative Care – Acute 13. RMN – MH 14. RMN Older People's MH 15. RMN – Older People's MH

*Each participant's primary role is described but many participants held other roles as carers or former patients/current patients as well as their professional role.

6.2 Co-Design Workshop 1 Findings

The first stage findings are reported in Table 14 Content and Table 15 Format and discussed under the themes of Section 6.2.1 (Content Features) and Section 6.2.2 (Format Considerations).

6.2.1 Content Features

Each cohort had representatives from mental health, PEOLC and patient/carer representation. Patient and carer representation were more limited than representation from clinicians, which was expected. Interestingly, each group had several participants who had multiple roles i.e. member of staff who was also a carer; patient representative who was also a carer, staff representative who had also been a previous service user. This added a richness to the discussion and created a greater sense of equality and shared experiences within the group discussion. Reflections by the two facilitators included comment on the liveliness of the discussion and that the range of participation by different members felt balanced. This is not always the case in mixed groups, where often one or two group members dominate.

Twenty-one content topic areas were identified in the data analysis process. The topics ranged from information on different conditions to patient and carer stories. The 21 content topics can be grouped into themes/types: Experiential, Information and Learning Content and are reported in Table 14.

Table 14 Content

	CONTENT		
	Data Item	**Topic Area**	**Emerging Ideas/Questions for Workshop 2**
EXPERIENTIAL CONTENT			
1.	- Patients/service users talking about how it is for them - Information isn't just theory, hearing the patient experience that you otherwise wouldn't is information too - Case studies - Interactive workshops, role plays - When people don't know what to do they seek information – when actually it is about changing attitudes not gaining knowledge – building confidence	Patient Stories - Case studies - Patient experiences	Changing attitudes in clinicians Building confidence in clinicians Competency not just information
2.	- Carer stories	Carer Stories - Case studies - in conversation with clinicians	Changing attitudes in clinicians Building confidence in clinicians Competency not just information
3.	- Education/role play/good practice in undertaking ACP with vulnerable groups of patients - Experiences of staff and patients - Examples of where clinicians feel it went well, what did they do? - Sharing practice ideas	Clinician Stories (clinical experiences, good practice and learning)	Participants felt it helped in the workshops to hear from other professionals and wanted to include similar conversations/accounts in the resource Resource needs to build confidence about how to have ACP conversations in a meaningful way with people with SMI
INFORMATION CONTENT			
4.	- Tackling challenging behaviour - Managing fluctuating mental well-being and possibly capacity - Management of acute mental health symptoms - Planning for when someone is unwell mentally in advance - Information about attachment and loss – how this may be more complex for some people with some mental health	Information on Mental Health Conditions and Symptoms Attachment and Loss	Explore balance of existing information and links to resources and creating new resources such as patient films etc

	conditions – personality disorder for example		
5.	- Huntingdon's Disease Association - MIND - Macmillan - Marie Curie - NCPC/Hospice UK - Royal College of Psychiatrists - St Mungo's - ReThink	Links to Other Organisations	Workshop 2 – what others available?
6.	- Link worker in MH to liaise with re medication interaction with EOLC medication/prescribing - Specific information on mental health medication at end of life and impact on EOLC prescribing - Need for liaison between MH and PEOLC	Medication Information and Advice	Some could be covered in this resource but also included in recommendations for practice – partnership working and care co-ordination elements Could include 'role of the specialist palliative pharmacy' in who's who section for example
7.	- Human Rights Act - Mental Health Act - Mental Capacity Act - Safeguarding Vulnerable Adults - Deprivation of Liberty - Next of Kin - Equality Act - Information sharing protocols – good practice examples - Permission to share information - Barriers – concerns around confidentiality - Advance Care Planning Inc. DNAR - Understanding restrictions around sharing information about a patient -	Legal Issues	Clarity about where these may impact upon where a person can receive EOLC, explanation for PEOLC staff who may not be as familiar as MH staff Requested by staff more than patients – risk and legal information Patient permission/confidentiality- links to ACP and Care Co-ordination in general
8.	- Policies and procedures all in one place - MH and PEOLC and other such as NICE guidelines etc	National Guidance, Policy, Good Practice	Also arose in previous study – different policies/strategies from different disciplines needs to be brought together – e.g.MH staff had no awareness of the Ambitions for Palliative Care

9.	- Assessing risk - Managing risk - Sharing risk information - Person-centred care v managing risk/rules - Hospice process re suicidal patients – is there one? - Clinician fear of opening up discussions and causing distress and increasing risk - Different services assess risk differently - Perceptions of risk are variable	Risk Issues	Clinician focus on risk – see patient interviews where patients say clinicians focus too much on risk – explore in workshop 2 What do people think the risks are?
10.	- Jargon buster - Explaining acronyms - Explaining clinical tools, methods and models	Glossary	Could be an extended glossary – explain a bit about culture and or models of care as well?
11.	- We need information on assessment – of people with MH and EOLC needs	Assessment Information and Skills	Links to Legal, Information Sharing and ACP Links to existing resources Underlying issue that assessment of people with SMI and terminal conditions is different to other assessments See 'difficult questions'
12.	- Make use of all the existing resources – they need to be in one place - Central point for info and resources that get lost on web - Links to relevant websites - The worlds of PEOLC and MH are separate so clinicians don't know what's available – bring it all together - Existing resources: - 5-step approach and RAG charts - Treatment models and pathway information - Advanced Communication Skills resources - Age UK resources about EOLC	Bring together existing resources	Inform question for workshop 2 Existing resource ideas need to be checked and reviewed/verified

	- Video – 'Can You See Me?' - Health Talk - Worcester University dementia film - Vincent Feletti obesity studies - Health Unlocked - ALD Manchester resources - Regional strategy/policy - Scottish ACP resources - COPD leaflets from association? -		
13.	- Where to refer people to? - Local and national - Psychiatric/MH services available and how to access - Palliative care services available and how to refer - Statutory and VCS/Charities - Social prescribing	Service Directory	Link to care pathway theme Local and /or national?
LEARNING CONTENT			
14.	- Mental health team – info about terminal conditions, guidance about thinking about prognosis, when to refer and to whom - Plan for support through the dying phase for MH team – what support will be needed? - "the only conversations I have had about death and dying while studying as a mental health nurse is suicide prevention and nursing suicidal patients" - Information about the reality and finality of EOL diagnosis for MH staff - Induction input about care through the life course including EOLC (challenge the perception that 'we' don't do EOLC* - Psychiatric/MH services available and how to access	Care Pathway Information – What does good palliative and end of life care look like for people with SMI?	Links to 15 and 20. And Myth-busting and Overarching Messages *relates to staff inductions – local issue, however could resource include a short film which could be used for induction? What are the rules? Isn't this person-centred care/flexibility? One size doesn't fit all?

	- Palliative care services available and how to refer - Building confidence through alleviating anxiety and reducing fear in staff (and patients) - Permission to bend the rules - Fear of the unknown - Flexibility - Thinking outside the box - Building relationships - Confidence - Advocacy - Permission to be flexible/person-centred		
15.	- Professionals should be able to share more easily information and experience - How do we share information when person is too unwell? - Barriers – concerns around confidentiality - HCP information – who is involved in a person's care? - Patient info available to all HCP's involved in care - Information sharing protocols – good practice examples - Contact numbers – who do I want to be contacted (patient) - Dementia content* - Understanding the dying process in non-cancer e.g. motor neurone disease, COPD, heart failure, Huntingdon's disease, multiple sclerosis, Parkinson's disease - End of life care plan - One-page document about wishes and preferences (rather than legal documents) - Essential information – what are people presenting with?	Examples of good EOLC Plans and Resources (inc. non-cancer conditions)	Explore in workshop 2 – what is good EOLC? Is this an overarching message (see below)? Link to issues surrounding Information Sharing and Partnership Working – local implementation issues but some 'how to…' type information could be included? *Separate resources available for dementia – beyond study remit; however, for patients with SMI who develop dementia there may be some benefit in including dementia specific information/content

	- Planning tool – what is happening? What is planned? Who is involved? - Information stays with the person		
16.	- Practical information – - Who is out there? - Who does what? - What about out of hours? - Contact numbers? - Referral points: when, why, how? - Key questions you could ask when you see a consultant (patient-focused) - Timing – when to do what?) staff section) - Communication - Communication skills - Encouraging knowledge sharing scenarios - Connecting teams/meeting in person - Access to other professionals/teams – so you can ask questions easily - Cross speciality working - Capitalizing on awareness days to share info, make use of trust wide communications	Who is Who? Who does what? When to refer? Where to refer?	Links to service directory and care pathway Emergence of idea of broader audience than staff/clinicians to patients and carers Community of practice Interactive resource Q and A online Local or national level – could content be tailored? Format question
17.	- Resources for patients and carers - Service directory - What to expect/what to ask? - Care pathway - Film explaining roles, support available, finance, who's who? - Explaining the range of services available	Information for patients and carers	Question about audience – see format and question for workshop 2 Links to use of visual methods
18.	- Staff being able to ask questions without judgement - Early conversations and how to have them - Difficult conversations - Allaying anxiety - 'end of life discussions should feel difficult'	Difficult Conversations	What are they? How to have them? Good practice Language to use Reducing fear and anxiety – talking about death and dying Communication Skills What are difficult conversations? Is this different for MH and PEOLC and Patients/Carers?

	- "It is difficult, if it doesn't feel difficult you aren't doing it right"		Benefit of hearing an PC Consultant say this within the group on MH staff present
19.	- Communication skills to support healthcare staff communicate with MH patients - How to connect on a personal basis - Building rapport with person - Conversations - Check with patient and family how much they want to know - How to support open and honest discussions - Empowering patient to talk - 'Tell me what I want to know'	Communication Skills	Much of this is common good practice in MH and PEOLC but not delivered to this patient group – sounds like recommending what is already known to be good practice – resource aims to tackle the 'how' of this Links to ACP skills
20.	- Person/family at the centre - Person in centre always - Variety of starting points (access points) - Dispelling myths - Acknowledge negative past experiences in healthcare of people with MH illnesses - May impact in treatment choices - Myth busting – "you won't always have pain" - Stigma challenging regarding cancer and other illnesses - Stigma challenging around EOLC and PC	Myth Busting and Challenging Stigma - Mental health, palliative and end of life care, death and dying	Significant topic of discussion and recognised need linked to use of visual methods in format discussions What are the myths? What format would best challenge stigma? – questions for workshop 2
21.	- What does a good death look like? What does a good death mean? - Everyone deals with end of life care (all clinicians) - "Mental health isn't a barrier to receiving good PEOLC" - Culture change – being able to talk about death - "Dying is everywhere" - Philosophies and practice in MH and PEOLC – views of death and dying in	Overarching messages - Background information on MH and PEOLC - difference in philosophies	Significant topic of discussion – what are the messages? Clarify audience to clarify messages – take to workshop 2

	MH very different to in PC – negative outcome - Definitions and explanations of what EOLC is, PC, where and who deliver, how to access etc		

6.2.1.1 'Experiential Content'

This theme relates to the content which participants suggested that is narrative or experience-based. Participants identified three groups – patients, carers and clinicians whose experiences they felt it would be helpful to include in the content of a resource. 'Patient stories' included patients talking about their experiences of accessing care, the barriers they experienced, examples of good care they received, sharing their views. Participants discussed how their views about patients were often changed by hearing their stories and experiences first hand. It is not always possible for clinicians to hear patient's stories first-hand in either their training or in clinical settings. Participants felt including patient accounts would be an important component in building confidence and changing attitudes about patients with SMI and terminal illnesses.

Similarly, the views of carers were identified as another useful content feature. Carer participants had identified the dichotomy they feel between being ignored by professionals and being expected to be experts. Participants felt that carers' experiences were also helpful when a patient's views couldn't be heard, through illness or because they were deceased. Participants also felt carers often had experiences to share which could improve care and services because they can identify where care could have been better.

The 'clinician experience' content was slightly different. Participants identified areas of clinical practice they found difficult such as dealing with challenging behaviour or undertaking advance care planning with mentally unwell patients and felt that including other clinician's experiences of tackling these issues would be useful content. Hearing first-hand and learning from accounts of how colleagues, particularly from across professional disciplines, have approached these areas was felt to be useful content for the resource. Participants felt this would be more accessible than a good practice guide for example.

In addition to being 'types' of content that participants would like to see included, using patient, carer and clinician narratives to deliver other forms of content was a recurrent format idea. Some of the format ideas in Section 6.2.2, for example case studies, patient and carer narrative films and clinicians in conversation with each other on film, were also suggested as format types for delivering content.

6.2.1.2 'Information based Content'

'Information based content' relates to the type of content which is guidance or policy-based, such as existing NICE guidelines, legal information, risk management information and glossaries of terms for example. Clinicians reflected that there are many existing useful resources available but that finding them, having time to find them, or knowing which ones are up to date is problematic and time-consuming. Comments were made about not knowing what was 'good quality' information and where to find it outside each participant's specialism. Suggestions were made to include links to other organisations websites, government guidance such as the Ambitions for End of Life Care (National Palliative and End of Life Care Partnership 2015) and the Five Year Forward Vision for Mental Health (Mental Health Taskforce 2016).

Content on specific issues, such as assessment and communication skills, information on different mental health conditions and symptoms, was also suggested. Areas where clinicians felt underconfident and wanted clear information included managing risk, legal issues and legislation. Medication information and advice were also identified as necessary. Suggestions for clarifying the jargon acronyms and specialist language used in both mental health and in palliative and end of life care was suggested in the form of a glossary.

6.2.1.3 'Learning Content'

The third 'type' of content that was highlighted is described as 'learning content'. This refers to content that participants felt should be included, which aims to provide the audience with new information, rather than simply linking to other resources. Content which aims to challenge perceptions or thinking. It would be less likely to be presented as policy and guidance documents of references, and more likely to be presented in creative ways. One example of this type of content is 'Overarching Messages'. The groups felt that there are some key messages about both mental ill health/mental health services and about palliative and terminal conditions/PEOLC that the user of the resource would need to know. Examples of these overarching messages were 'We all [clinical staff] do end of life care' and 'Mental ill health is not a barrier to receiving end of life care'. The participants felt that some overarching messages should be included to set the tone for the resource, and to indicate who the resource is for. There should be links to wider initiatives which aim to improve conversations about death and dying, and mental health awareness more generally.

This linked to another example of this type of content, which the groups felt should be included – 'Myth-busting and Challenging Stigma'. Participants from all backgrounds were very aware of the myths and stigma surrounding mental illness and death and dying and wanted to develop content which challenged these myths and changed attitudes. Other types of learning content identified were Difficult Conversations (and how to have them), Information about the Care Pathway, Examples of Good PEOLC Plans and resources and information about both the mental health system and the PEOLC systems, including staff roles and responsibilities. Participants also felt including content about communication skills would be useful and support the other content identified.

6.2.2 Format Features

Five themes were identified in relation to format features of the resource. Format relates to the ideas the workshop groups had regarding how the content could be presented. For example, presentations, guidelines, films, and the important qualities of the resource such as being accessible, feeling reliable and being interactive. Each of the themes is presented in Table 15 with the original data items, to illustrate how the themes were developed. The third column highlighted the emerging ideas or questions which informed the design of the second round of workshop activities.

6.2.2.1 Accessibility

Participants identified that time to attend, and access to funding, for training is an issue in many clinical settings so developing a resource in a traditional face to face course format was not useful. PEOLC clinician participants also highlighted that although patients with SMI don't make up a large percentage of their caseload, they are often the patients who raise anxiety in clinical teams. It was recognised that it is unrealistic to have access to dedicated mental health staff in PEOLC teams and services in the current health economy, so a resource that included some of the mental health expertise which the PEOLC staff felt they were missing was welcomed in all of the groups. Participants felt that they needed to be able to access information easily and when it was needed, rather than attend a one-off course held at a specific time.

Table 15 Format

FORMAT			
	Data	**Theme**	**Emerging Idea/Question for Workshop 2**
1.	- Need to make sure people know it's there - Information available before you need it – make it a go to resource - Easily retrievable in the clinical setting - Time is a factor – we need timely access - Accessing patient data takes too long for frontline staff in acute settings* - Right information at the right time - Web-based - Intranet/internet-based - Easy to find – accessible - Information on a web is publicly available, so why not make it intentionally publicly available? - Workbook - E-learning courses	Accessibility	Web-based resource Could incorporate e-learning content Allows for the range of content identified to be included and widest access regardless of geography or clinical setting Should it be accessible to a) patients and carers and b) general public? This would also incorporate any clinician not just the ones the groups identified *Relates to idea of patient-held care records type app – recommendation for further research?
2.	- Interactive - Discussion forum - Twitter feed - Q and A's - Opportunity to ask questions	Interactive Resource	Could it function as an online 'community of practice'? Social media impact could be incorporated to maximise reach?
3.	- Crisis teams (MH) - Education teams (MH and EOLC) - Communicate to CMHT staff - 'longer-qualified' staff - All teams through the life course - Available to everyone – nurses, clinicians, patients – it would be powerful to see everyone's perspective - Format appropriate to all? - A resource which crosses boundaries – consider where it is hosted? - EOLC whose role is it anyway? - Everyone's - Can one resource support different professionals, families, friends, carers and patients – capture all perspectives	Audience	Emerging idea about equity – is it for everyone? Do patients need to build their confidence in the same way as staff? Do patients and carers need the same or different information? How and where should it be hosted to maximise legitimacy and reach – i.e. if it were hosted by a palliative care professional body would that preclude MH clinicians from access/knowing about it/feeling it was for them? Is NHS England website too strategic? Is an independent resource perceived as trustworthy? Which brands/organisations are trusted? Requires further exploration in second round of workshops

			Hosting issues to maximise accessibility – informed question in workshop 2
4.	- Film clips, short written experiences, images - Different formats, engaging in conversation through film, story, presentation, case studies - Short film clips/video 'how will this diagnosis affect my mental health?' - Short videos for training - Bringing together all the current useful content on YouTube etc - Video - Move away from book taught approaches to more creative approaches - Films/role plays - Blogs, videos, day in the life of… - Videos – carers, patients and staff in conversation	Creative and Visual Methods	Web-based resource using these methods would allow wide range of content to be included – even 'how to…' examples of content which appears to be only locally-implementable such as work shadowing and holding partnership forums And Types of content such as Death cafes, best practice through filmed role plays etc. Maximise impact of patient narrative Previous study found this is one of the things which changes staff attitudes
5.	- Flexibility - Inclusive language - Personalised/individualised - Must feel nice to use/handle - Colour important	Qualities of Resource	Requires further exploration in second workshops – which websites and apps achieve this? Where do clinical staff go for information? What feels a legitimate source?

Two participants from acute hospital settings highlighted how difficult it is to find out information about patients when time is limited. This led to a discussion about a patient-held care record. This falls outside the remit of this study but may be considered in future research. It was also emphasised that whatever format the resource took, the challenge would be to raise awareness of the existence of the resource to the intended audience. This informed one of the questions in the second round of workshops.

Participants felt a web-based resource would be beneficial in that it could be used by any clinician or team wherever they were based in the country (or internationally). Some of the discussion about content linked to sharing best practice and a web-based resource would allow best practice to be widely shared. Participants also highlighted e-learning as another approach to addressing similar issues about ability to access funding and time to attend training. However, participants also stressed the volume of statutory and mandatory training now delivered via e-learning in the workplace and felt that this sometimes de-values content.

6.2.2.2 Interactive Resource

As the discussion across the three cohorts developed, participants felt that the resource needed to be more that a one-way 'content-to-audience' resource. The need for interactivity was highlighted and the groups felt that a format which allowed the audience to ask questions, debate and discuss, as well as share practice, was important. The principle of a web-based resource, which included an interactive 'community of practice' inspired discussion forum, emerged within the first round of workshops.

6.2.2.3 Audience

The cohorts were made up of clinicians, patients and carers from mental health, PEOLC, primary and acute care. Although the aim of the co-design process was to develop the content and format of a resource which aims to improve care through building the confidence and challenging stigmatised attitudes of clinical staff, the cohorts discussed the need for information for patients and carers as well. One of the ways participants identified that care is often improved is through patients and carers having awareness of what services and care are available. The groups highlighted that often people with SMI are used to being passive recipients of care and do not hold services to account when care is poor. The reluctance of people with SMI to seek care due to negative past experiences also contributes to this. One participant questioned that if the resource was web-based, then it could also be available to patients and carers, which may support them to be better informed as well. This was not within the original scope of the study but provoked an interested discussion and will be re-visited in later development of the resource.

Participants demonstrated the wide range of professions and range of clinical settings they are located within, and therefore it was important to consider how the format of the resource might appeal to this broad audience and its availability to all who may need to access it. This informed a question about where the resource should be hosted, which was included in the second round of workshops.

6.2.2.4 Creative and Visual Methods

Participants highlighted the different formats that could be used to present the range of content. All groups identified examples where film is used to tell patient stories and how these impact upon clinicians in a different way from reading about patient experiences. Although much of the content identified initially related to guidance, policy and procedure, as the conversations developed, participants began to discuss the importance of hearing

patient and carer experiences. Clinicians, especially from different backgrounds, being able to talk to each other was seen as a valuable feature of the resource, and the groups identified ways to increase the access to the benefits of these conversations were to use film to capture patient and clinician experiences, film role plays and use web-based formats to share with others who could benefit. This supported the principle of the resource being web-based and maximising the benefits of technology and visual methods.

Participants developed the discussion from thinking about how film could be used, to thinking about the impact of other visual and creative methods, such as sharing art and poetry. Several participants felt that sometimes a piece of art or a poem had had a greater impact on how they felt about a marginalised group than formal training about equality and diversity.

6.2.2.5 Design features of the resource

The other theme, which was identified in relation to the format of the resource, related specifically to the design features. The language used, the 'look and feel' of it were felt to be important. Participants highlighted the differences between different websites and apps and how some felt more pleasing to use than others. Colour and style, as well as ease of use and inclusivity of language, were all highlighted as important issues. This informed another of the questions for the second round of workshops.

Data was identified in the stage one data analysis, which related to other forms of content. One group was themes which fell outside the remit of the study (see Appendix 5). The second group was ideas for content which may not immediately seem relevant to the development of a web-based resource, but which required further discussion about how they could be included. These are outlined in Table 166. These themes were used to inform the discussion in the prioritisation task in the second round of the co-design workshop process.

Table 16 Wider issues

SERVICE-WIDE/STRUCTURAL/LOCAL ISSUES – FOR DISCUSSION/GUIDANCE INCLUSION			
	Data item	**Topic area**	**Emerging idea/question for workshop 2**
1.	- Training each other (MH and PEOLC) - Peer education - Death cafes - EOLC Conferences – who would run? - Forums - Schwarz rounds - Joint MH and Palliative Care day once a year - Networking - Drop-in sessions - Local and national training programmes - Newsletters – who is going write them? - Time and resources limited - Input to core professional training	Peer Training/Cascading Training Death Cafes Conferences/Training events Reflective Practice Sharing resources	Ideas for the way in which information could be shared, but acknowledgement of the limitations in knowledge and resource – some acknowledgement that these haven't worked before Time and resource intensive – but how many of these ideas could be incorporated into an e-resource
2.	- Students learn best through seeing – hospice placements - Hospice placements - Cross boundaries – mental health nurses on hospice placements - General nursing students on mental health placement - Work shadowing	Work shadowing, hospice and mental health placements Core training – change to curriculum	Experiential learning across placements
3.	- To improve staff induction, have champions MH and PEOLC - Link workers? - Key workers? - Accompany patients to appointments - Advise other staff about PEOLC issues in MH and MH issues in PEOLC - Contribute to the development of strategy documents	MH and PEOLC Champions Link Worker Role	'How to' guides could be included, even though these are local/national initiatives/working/arrangements/ recommendations
4.	- Empowerment from the top down - Organisational culture (MH) - EOLC Champions - Input to staff induction (MH)	Organisational Culture Input to staff induction (EOLC in MH Trusts and vice versa)	Examples of how senior leaders set culture Examples of the 'champion' role – what do they do and why is it beneficial?

6.3 Co-Design Workshop 2 Findings

6.3.1 Prioritisation Exercise Results

The final clustered themes relating to content were used to inform the first task of the second round of co-design workshops – prioritising the content. In co-design groups, it is not possible to attribute weightings to data based on the number of times a theme arises, because it may have been written down only once but discussed at length by many participants, for example. Allowing the participants to prioritise their own content generated in the first workshop creates an opportunity for the data to be checked by the participants and then weighting or significance attributed to the content.

- All 21 topic cards were organised into high, medium and low priority by each group and Table 17 shows where groups agreed on the priority or inclusion of each topic.
- If a topic was prioritised as high priority by all cohorts, or where it was categorised as high and medium by all cohorts, it is shown in bold and starred.
- The 12 topics which the groups were to discuss were provided on blue cards and those which were deemed to be important to include, possibly in the form of guidance or 'how-to' information, are included in Table 18.

Table 17 Prioritised content

Blue – Cohort 1 and 2 Green – Cohort 3

High Priority	*Medium Priority*	*Low Priority*
***Overarching Messages** ***Overarching messages**	Medication Information and Advice	Legal Issues Legal Issues
***Care Pathway Information**	***Care Pathway Information**	
***Communication Skills** ***Communication Skills**		Risk Issues Risk Issues
***Difficult Conversations** ***Difficult Conversations**	Glossary	Glossary
	***Examples of Good EOLC Care Plans and Resources** ***Examples of Good EOLC Care Plans and Resources**	National Guidance, Policy and Good Practice National Guidance, Policy and Good Practice
***Myth Busting and Challenging Stigma**	***Myth Busting and Challenging Stigma**	Links to other organisations Links to other organisations
	***Clinician Stories** ***Clinician Stories**	

*Patient Stories	*Patient Stories	Information on different mental health conditions and symptoms Information on different mental health conditions and symptoms
*Carer Stories	*Carer Stories	Medication Information and Advice
*Information for Patients and Carers	*Information for Patients and Carers	
*Who's Who?	*Who's Who?	
*Service Directory	*Service Directory	
*Assessment Information and Skills	*Assessment Information and Skills	
	Bring together existing resources	Bring together existing resources

The topic themes which were agreed to be high priority across all cohorts were:

- Overarching Messages
- Communication Skills
- Difficult Conversations

The topic themes which were agreed to be high and medium priority across the cohorts were:

- Myth-busting and Challenging Stigma
- Care Pathway Information
- Patient and Carer Stories
- Information for Patients and Carers
- Who's Who?
- Service Directory

Clinician stories, as well as examples of EOL Care Plans and Resources, were included as medium priority. Low priority topics included legal issues, risk issues, national guidance, policy and good practice and information on mental health conditions. Interestingly, these were some of the first topics identified by the groups in the first round of workshops when they began to think about what content might be needed to achieve the aims of the resource – to improve care through improving the confidence of clinicians and challenge some of the stigma and fear which underlay attitudes to people with SMI.

There were some ideas for content which fell outside the remit of designing a resource, but that participants felt would help build confidence in clinicians, such as running Death Café's, arranging hospice placements, sharing supervision across mental health and PEOLC and improving content relating to death and dying and mental illness on core professional training courses. Although most of this type of content would have to be implemented locally or nationally, participants felt that some could be included as 'how to' sections on a web-resource. This is presented in (Table 18).

Table 18 Content for discussion

Blue – Cohort 1 and 2 Green – Cohort 3

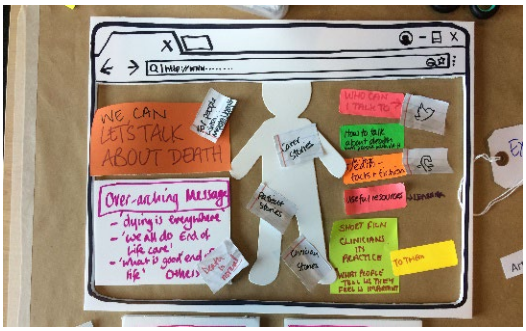
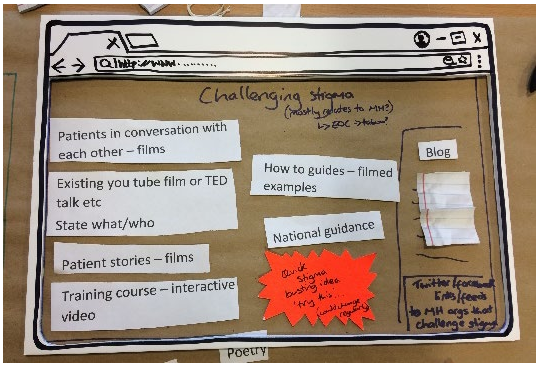
How to implement:	***How to implement:***	***How to implement:***
****Death Cafes***	****Death Cafes***	*Organisational culture*
	Input to core training	
	Reflective practice,	
	Schwartz rounds, MDT,	
	case conferences	
	MH Champions	
	EOLC Champions	
	Link worker/key	
	worker/care co-ordinator	

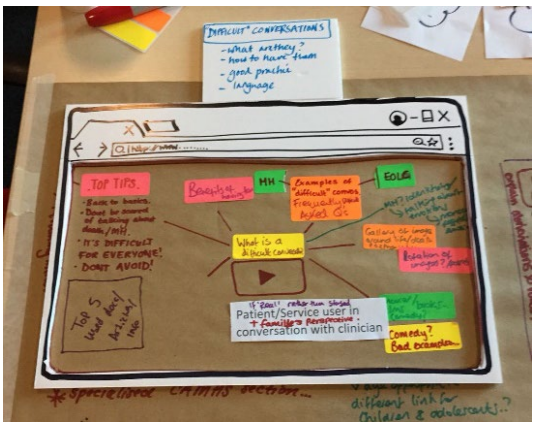
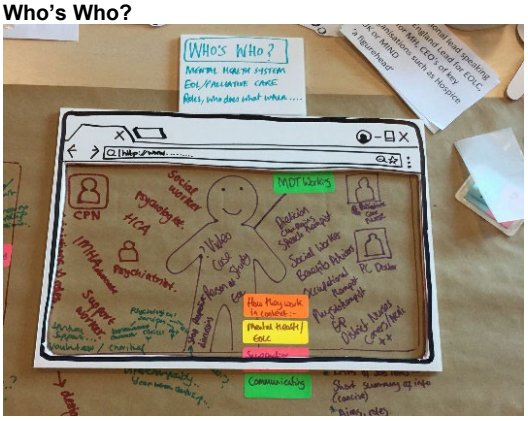
6.3.2 Task 2 – Paper prototyping

The second task in the co-design workshop was to take the prioritised content and format preferences from the first workshop data and use it to create a prototype design and webpage screens for the resource. This process used photographs of the original artefacts created within the co-design workshops. Each cohort split into small groups and took some of the high prioritised topics and format preferences and used a paper prototyping method to begin to create the screens (Table 19). Larger format images of all the prototyped screens are included in Appendix 7.

The paper prototyping process provided rich visual data. In a time-restricted study the full concept and content of the resource cannot be designed by participants, however, the paper prototyping allowed participants to really think about how the resource would work, about what it needed to say and do, and how different types of information could be best presented Participants also discussed functionality and considered different audiences and how they might interact with the resource. The description of the resource developed is presented in Section 6.4 towards the end of this chapter and the key features are discussed in Chapter 7 (Discussion).

Table 19 Paper Prototyping Process

TOPIC	CONTENT	FORMAT RECOMMENDATIONS	NOTES
Overarching Messages 	• 'We all do end of life care' - • this resource is for everyone involved in the care of people with SMI and terminal conditions • What happens at the end of life? • Let's talk about Death • What does good end of life care look like? • People with Mental health problems die too… • What should I do if my patient is terminally ill? – for MH professionals • What should I do if my patient has a mental illness? – for PEOLC staff • Dying is everywhere – normalising death • Choice at the end of life – how can we help people with mental health problems have the end of life care they want? • Who can I talk to? - patients	• Short films • Clinicians in practice • Patient stories • Clinician stories • Carer stories • Links to useful resources (pre-existing) • Clinicians talking across discipline – CNS talking to RMN, palliative care consultant and psychiatrist • Links to ACP guidance and good practice	• Participants felt the opening page should set a tone of openness about - death and dying - mental illness - about professional roles • general information, links for different audiences to follow • clear links to patient and carer content if appropriate • participants felt planning ahead was a crucial aspect of ensuring better care, earlier referral to palliative and end of life care and shared planning between MH and PEOPLC was essential • how to go about this guidance was important within the resource
Myth-Busting and Challenging Stigma 	• Challenging stigma about mental ill health • Myths about risk and mental illness • Challenging stigma about hospice care • Palliative and end of life care • Breaking down taboos about talking about death and the end of life	• Participants suggested some myths could be challenged through: - films of patient stories - case studies – written - films of conference presentations - patients in conversation with each other - links to existing YouTube content e.g.TED talks - Training courses – interactive video - Poetry • Each myth/fact have a hyperlink to appropriate content • Make use of existing online resource by using links	• Some clinicians expressed their fear about people with mental illness, risk to personal safety • Some patients felt that clinicians focus too much on risk to others and that most people with mental ill health are most risk to themselves • There was widespread agreement about the myths and stigma surrounding mental ill health and palliative and end of life care

		• Blogs from different patients and clinicians could be used • Interactive elements like Twitter feed and Q's and A's	
'Difficult Conversations'  	• What are difficult conversations? • Why do we find them difficult? - Why Me? - Am I Dying? - How does your mental health affect you? - Questions about risk and previous harm to self or others - Questions about prognosis - Asking 'personal' questions - Questions which clinicians fear will upset the patient	• Examples of what the types of questions are • Links to patients and clinicians in conversation • Film of patients in conversation with each other or to camera • Downloadable 'how to' guides • Case studies – good and bad practice • Real examples rather than actors • Use of top tips • Suggestions of language • FAQ's • Communication skills training – values rather than knowledge-based	• Mental health participants found conversations about death and dying more difficult • PEOLC participants found conversations about people's mental health history more difficult • Patient and Carer participants found the way clinicians approached conversations difficult rather than the subject of the conversation • For MH practitioners – being asked about service users physical health care? • For all practitioners – not knowing 'who knows what' and fear of asking the 'wrong' thing? • Participants felt the way questions were asked rather than what they were was most important – values-based approach was suggested – professional curiosity, empathy, open-questioning, patient-focused, patient and carer as expert • Active listening
Who's Who?  	• List professions involved and who does what • Explain the different teams patients and clinicians might encounter i.e. community palliative care team, community mental health team, district nurses, GP, health psychologist, dieticians, different AHP roles • Information about services available	• Video case study explaining the care pathway, who might be involved, what roles people occupy • Link to local information about structure of services – could link to service directory • Short films about different services i.e. many hospices have a film about their services available – links could be included	• People with both mental ill health and terminal conditions have many clinicians involved in their care and there is confusion about roles and responsibilities • Clinicians agreed they find it hard to understand the different roles and services available outside their own discipline

6.3.3 Task 3 Sources of Information and Branding

Finally, the groups were asked to consider two additional questions; 1) where a future resource might be hosted to maximise impact and accessibility and 2) where clinicians might seek information from. In recognition of the use of emerging technology and social media in healthcare by clinicians, the question of where participants feel they *should* go for clinical information, and where *in reality* they turn to for information was also asked. Secondly, participants were asked to consider what existing resources they were aware of which might be included within a new resource. A summary of ideas is presented in Appendix 6 and will be used to develop the prototype resource further, following conclusion of this study.

Table 20 Sources of information

Source	Where do clinicians feel they should get information?	Where do clinicians actually get information?	Participant comments (from field notes)
From patients	●	●	Some clinicians felt that they should know, and shouldn't be asking patients, patient and carer participants felt they should be asked more and that they had a lot of expertise
NHS England	●	●	Via email updates rather than website checking
Universities	●		
Service User Organisations	●		Patients and carers found SU organisations to be good sources of information
Research Organisations i.e. NIHR	●	●	Via email updates – some clinicians only
Institute of Mental Health		●	MH clinicians
Local Guidance		●	Varied by location
Other professionals	●	●	Common although geographical differences depending on relationships locally noted
Books	●		Participants commented that they used books when they were

			students but less and less as practitioners
Journal Articles	●	●	Participants commented that journal subscriptions were very expensive and only accessible for students or qualified clinicians enrolled on post-qualifying University courses Clinicians felt journal clubs were useful ways of accessing current research but that they had very limited time to attend
CPD Training	●	●	Concerns about the reduction in budgets and time pressures to attend CPD were expressed
NHS websites	●		Participants commented that they preferred email updates or newsletters, which they would then follow web links on, if they were interested in the content
Charity websites	●	●	Participants commented that they had their 'go to' websites which they relied on heavily
Stories/Art/Poetry		●	Participants commented that this was what they often remembered more than traditional educational content
Twitter/Facebook Groups		●	Participants commented that this was becoming increasingly common way of keeping up to date, as subscriptions to journals had been cut back in their organisations Participants also commented that they liked being able to ask questions of other professionals
YouTube		●	Participants felt this was 'unofficial' but often a very useful source of information
TED talks		●	Participants felt this was 'unofficial' but often a very useful source of information

Palliative Care websites e.g. Hospice UK	●	●	For specific issues – varied by professional group
Mental Health websites e.g. MIND	●	●	For specific issues – varied by professional group
Recent evidence – via email update	●		
Email newsletters and updates		●	Some clinicians said they relied on internal newsletters and intranet updates
Conferences		●	Clinicians commented that budget restrictions made it less possible to attend

It was interesting to note that differences occurred between where clinicians said they felt they should get information and where they turned for information. Some participants were almost apologetic in the discussions about this. Patient and carer participants did not feel as though there were places they 'should' go for information, rather they just were aware of lots of different sources. However, clinicians identified that they felt they should get information or guidance from "reputable sources" such as NHS websites, books and university sources. In reality, they didn't and they felt that social media such as YouTube videos, TED talks and Twitter provided more useful information but were not 'official' and not where they should be finding information. The main issues raised were; having enough time to keep up with sources of information and participants liked email updates and 'one-stop-shop' type resources for this reason; trusting the quality of the information; knowing there was a lot of useful resources available but not being able to locate them easily; budget restrictions placed upon training, conference attendance and journal subscriptions and not being released from clinical work for CPD.

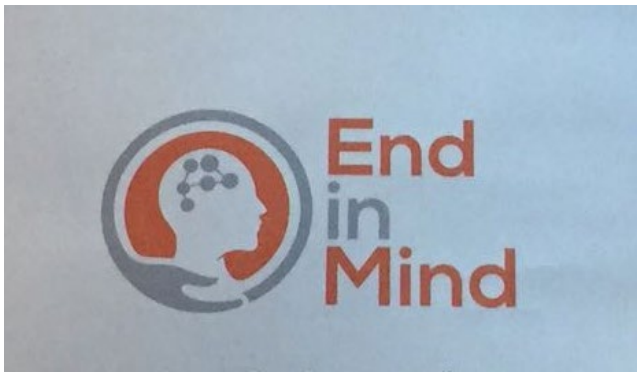
6.3.4 Feedback on Potential Resource Name

In earlier consultations it became apparent that referring to the resource and concept by the research title was unwieldy and that any resource designed would have to have a brand identity. Whilst recognising that this will be a part of a full pilot of the resource in the future, it felt important at the concept development stage to gain some ideas and feedback about this. The name 'End in Mind' had been discussed by the researcher in a clinical setting during the preparation meetings and PPI activity and the co-design workshops offered opportunity to gain feedback on this name. The researcher had run a

design competition through www.freelancer.com to develop some initial ideas for a logo or brand identity. Graphic designers can take part in the competition and suggest different ideas for brands and logos. The ideas can be presented and tested with different groups and individuals. The workshops offered a valuable opportunity to gain feedback on this idea and the concept of branding and logo.

Workshop participants were asked to give feedback on the brand and logo to inform future development.

Table 21 Feedback on 'End in Mind'

Cohort 1 and 2	**Cohort 3**
www.endinmind.co.uk 	
'Excellent name, like the logo' *'Orange is good'* *'Love the name End in Mind and the logo'* *'Logo looks brill'* *'not too NHS-ey'* *'professional but not officious'* *'accessible for patients and professionals'* *'great name'*	*'Would a picture of a brain be better than circles?'* *'Might not work for patients with brain tumour'* *'Like it'* *'The hand is nice, suggests a holistic approach'* *'fab logo'*

This initial feedback will inform the next, post-doctoral, stage of the development of the resource. Further consultation will be required before a full brand identity is identified and finalised, but useful insight was gained from participants initial ideas.

6.4 Description of the Web-based Clinical Resource

The previous sections have presented the key features of a web-based resource (in terms of content and format), as prioritised by participants in this study. This section presents a more detailed outline of the proposed resource. It draws on the findings from across the stages of co-design.

6.4.1 Outline of Web-based Resource – Summary of Key Elements

Each section has been developed from the data presented in Tables 13 and 16 in Chapter 6 (Co-Design Findings – Workshops). Key features related to the 'look and feel' of the resource developed with participants included: Accessibility, Interactivity, Breadth of Audience; Use of Creativity and Visual Methods and the Qualities of the Resource (see Table 14). The main aim was to create a resource which improved the confidence, knowledge and skills of clinical staff to improve practice when working with people with SMI and terminal conditions. These staff may work in a range of clinical settings and encounter patients and carers at different stages of their health journey. The building of confidence and competence does involve providing information and knowledge (Reeves et al. 2017) but in addition, to influence attitude change, challenge fear and reduce stigmatised views, other more interactive approaches are necessary (Haythornthwaite et al. 2007; Hill, Song and West 2009; Knaak, Mantler and Szeto 2017; Robertson and Jochelson 2006). As previously discussed, it is also important to challenge fear and stigma in clinicians through the use of real life patient stories and experiences, to develop greater understanding of the patient. Each section of the proposed resource incorporates the considerations of what participants prioritised as important content, the most appropriate way of presenting this content and the need to meet the qualities identified in the discussions of format (Table 14). The different types of content identified in the data analysis (Experiential, Information and Knowledge) were also considered in the way each section has been developed. Whilst the overall design and functionality will be developed in the post-doctoral stage of this work, with web designers as part of the co-design process, each section is described here in terms of content, purpose and format. A draft website map has been developed from the findings to illustrate the relationship between the sections (Fig. 19).

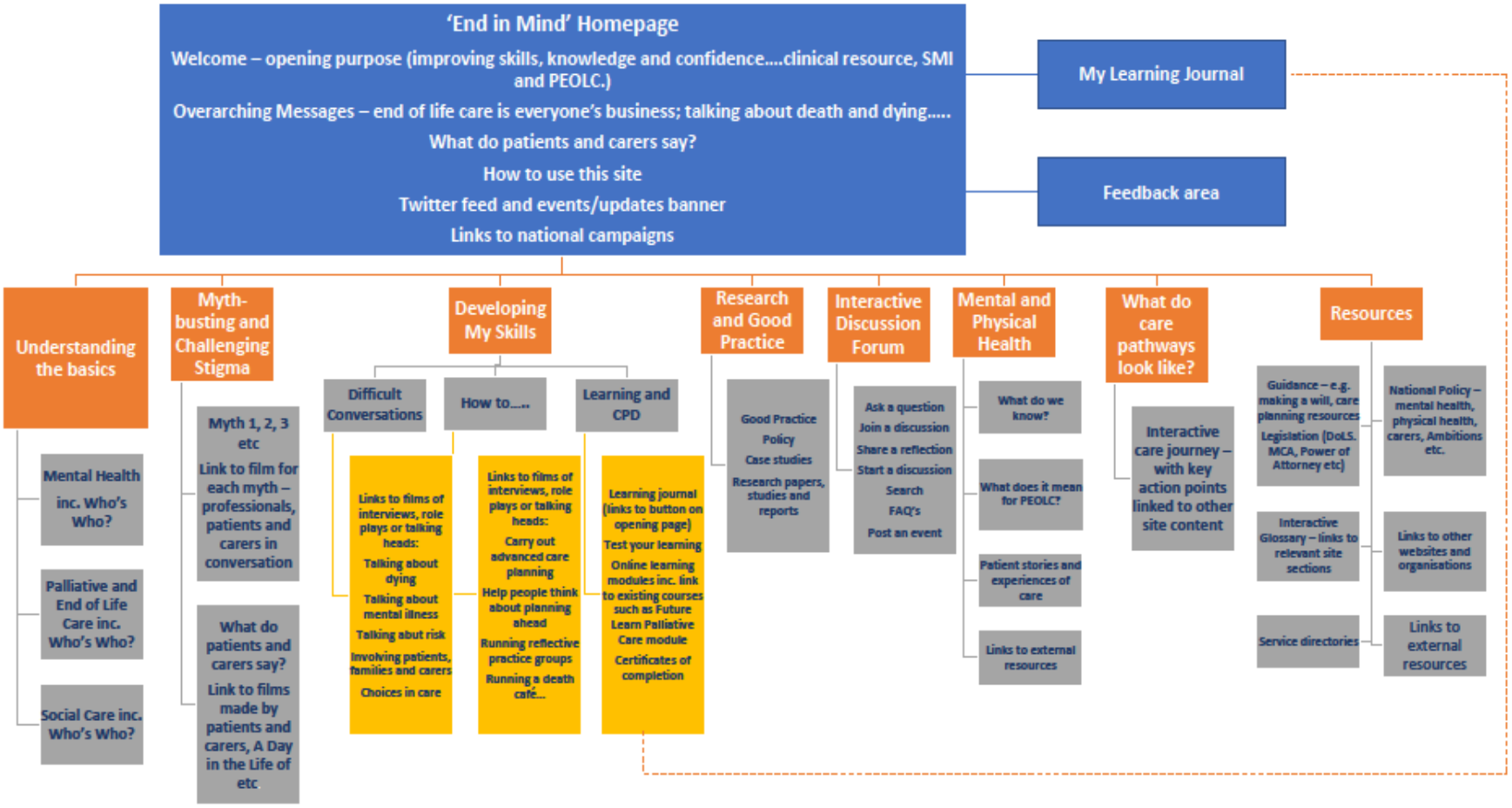


Figure 19 Indicative website map

Section 1 – Introductory Section: Overarching Messages – setting the scene

This section forms the first pages which the user will encounter. Its purpose it to introduce the resource, present the background and overall purpose for why the resource has been developed. Overarching messages were identified in the co-design workshops and will be included as titles with explanations, for example: 'End of life care is everyone's business'; Talking about Death and Dying; People with Mental Illnesses Die Too; What should I do if my patient is terminally ill? What should I do if my patient has a mental illness?

Based upon the workshop findings, the introductory section will present users with a series of icons to select and will also include opening video clips with patients, carers and clinicians setting the scene and presenting overarching messages. It is important that this section sets the tone of the resource, including clinician, patient and carer voices, creating an experience of interactivity and accessibility.

Section 2 – Understanding the Basics

- *Mental Health*

This section will provide users with information about mental health care, mental health conditions and how services are structured. Non-mental health participants reported a lack of knowledge about the mental health system and mental health conditions and how they affect people. This section aims to provide information and experiential content to improve users confidence, understanding of language and knowledge about mental health issues.

Case studies will again be used to highlight key issues, challenge stigma and prejudice, whilst providing information to users. Part of the purpose of the case studies is to highlight the complexity of health and social histories of people with SMI, thus giving understanding to clinical staff of how and why this may impact upon their ability and willingness to access services now. A mental health version of the 'Who's who?' information will be included to help users understand the different clinical roles within the mental health system. Like PEOLC, mental health is a multi-disciplinary, multi-located health system, which is complex to understand. This section aims to de-mystify the system to non-mental health users of the resource. Links to existing resources will be

included; for example HealthTalk films (with appropriate permissions). Learning will be re-enforced by quizzes at the end of each section, similar to an online learning module.

- *Palliative and End of Life Care*

This section will provide similar information about what PEOLC is, how and where it is delivered and who by. Mental health practitioners had little knowledge of the PEOLC system and the breadth of care it encompasses.

This section would also include a 'Who's who?' section which users can click on to understand the different clinical roles. Key information about the different types of acute, inpatient and community palliative and end of life care will be provided. Links to key organisations and documents will be included, which will link to content in Section 9. For example, links to campaigns such as 'Open up Hospice Care' and Dying Matters could be included.

Case studies illustrating the different ways patients access PEOLC will be included, to give users a sense of key referral points and the importance of early referral will be highlighted. Links to local service directories will be provided (making use of existing service directories and linking to the Hospice UK site for hospice care for example).

Section 3a – Myth-busting and Stigma

Participants identified that key barriers to the delivery of effective PEOLC to people with SMI are the myths and stigmas which surround both mental illness and death and dying. This section of the resource aims to challenge this through presenting each myth together with counter-perspectives. This section allows users to select myths they are drawn to, that they believe, or that they haven't come across before, answer questions and hear filmed accounts of a counter perspective to the myth.

Myths identified by participants include; people with mental illness are a risk; people with mental illness are not able or don't want to take part in care planning; talking about death and dying to people with mental illness will make them more ill; we should not talk about death; talking about death makes it happen more quickly; hospices are places people go to die; palliative and end of life care is for people with cancer; palliative and end of life care is for the last few days or weeks of life; palliative and end of life care is not my job.

Where appropriate, it may be useful to include links to other organisations, or existing external resources in this section, such as links to Hospice UK website and resources, Dying Matters resources or organisations such as MIND or ReThink.

Section 3b – What do patients and carers say?

This section will use patient and carer stories, presented as short films, to humanise people's experiences and help clinicians see the person behind the labels and diagnosis. This was identified as a significant issue for both clinical staff, patients and carer participants. Part of the rationale for using a creative co-design approach, rather than EBCD, was the lack of films concerning this particular group of patients, and their carers, available on existing resources such as HealthTalk. This group of patients are often hidden and their stories and experiences have not been previously heard in research or clinical practice. The findings of the co-design workshop stage and the previous clinician study identified that when clinical staff can see a patient as an individual rather than a set of diagnoses, they are better able to attune to the patient's needs. The aim of these films is to give patients and carers a voice to help staff do this.

Topics and themes which the films may highlight include those identified as problematic by participants – an over focus on risk for example, or the perception that people with SMI lack capacity. The films would also give patients and carers the opportunity to convey the complexity of their lives, personal histories and health conditions. A possible format might include 'A Day in the Life' style or a more traditional interview. Alternatively, and in line with the research design, control of the film-making could be handed to participants to ensure their stories are presented in the way they wish to present them. Innovative, participatory or user-led film methods, such as 'iphonography' and mobile-film (All-Party Parliamentary Group on Arts, Health and Wellbeing 2017; Halpern and Humphreys 2016; Mannay 2015) which align with the participatory philosophy of co-design will be adopted, in addition to traditional filmed interview techniques to enhance the impact of the patient and carer experience.

Section 4 – Developing my Skills

This section focuses on developing clinician skills. Yet, rather than through acquiring new information-based knowledge, it focuses on developing skills and confidence by allowing users to engage in experiential activities. Staff participants had identified certain areas of practice where they felt under confident. Some examples included Difficult Conversations, Involving Patients in Care Planning, Talking about Mental Health, Talking about Dying, Talking about Risk. It was acknowledged that for different professionals, different questions are experienced as difficult – for mental health staff talking about dying, answering questions such as 'why me?' or 'how long have I got?' were identified as difficult. For PEOLC staff, asking about a person's mental health conditions, or what

happens when they become mentally unwell and asking about risk issues were identified as examples of difficult conversations. However, as these discussions took place, participants began to share their experiences of having these conversations with each other and build their own confidence within the workshops, by hearing about how other colleagues approach these conversations in their practice. Patient participants were able to share their experiences of being asked such questions. So it became apparent how important it was that this resource uses films of patients in conversations with each other, with clinical staff, and with colleagues from different disciplines in conversations with each other. This section will also include filmed role plays of best practice and suggestions of how to start 'difficult' conversations so they begin to feel less difficult.

Learning will be re-enforced by questions and reflective activities at the end of each section, similar to an online learning module. To promote skills development and provoke attitude change, there could also be interactive scenarios where the user makes best choice decisions on a patient care journey. In addition, to promote reflection and consideration of the issues within the section, reflective questions will be posed and users encouraged to write reflections in the online learning journal and post questions for discussion in the interactive discussion forum.

To support the development of skills, knowledge and attitude change, there will also be an online reflective learning journal which staff can complete as they use the resource. Reflection is important in embedding learning (Cassidy 2004; Kolb 1984) and having a reflective journal embedded within the resource draws users to reflect as they interact with the site. This could be linked to CPD activity logging and could also support the evaluation of individual learning and the impact of the resource. The online journal could have the option to share questions, reflections or responses to the interactive discussion forum and the option for content to be shared anonymously with other site users or kept solely for the learners use. Using a reflective journal encourages reflection and as the aim of the site is to build confidence and challenge attitudes, it aims to encourage a more reflective approach as opposed to using tests which might test knowledge acquisition. Tests and quizzes are used within certain parts of the resource for engagement and quick knowledge checks.

Guidance and good practice for running reflective practice sessions for other staff will also be included, encouraging discussion and shared thinking about issues, barriers, fears and how to overcome them, when working with the patient group and their families. The films in each section could be used as trigger films to support reflective practice

discussions. The films will be made interactive, by including pause points where users can answer questions about what they have seen so far and what could happen next and identifying different answers to questions. All of the content in this section will be experiential and visual.

Section 5 – Research and Good Practice

This section has a specific focus on research and innovation. Participants reflected that unless they are on a training course, they no longer have access to journal subscriptions in clinical settings. Participants also cited time and relevance as barriers to reading current research. However, participants also said they found useful articles and papers on social media sites or email subscription lists, other professional groups and publications. The lack of a central repository for useful information and resources for people with SMI and terminal illnesses was highlighted, so this section would also allow users to upload content. In the future, this section could be developed to include the ability to upload a research article of the week, highlight key papers when they are published, highlight key research teams working in relevant fields, advertise studies to participate in and other research related activity. Conferences could be advertised (with banner links to the front page).

Section 6 – Interactive Discussion Forum

This section will be largely interactive in nature and led by the users of the resource. Participants were clear that any resource developed would need to be interactive to be useful. This section will have a discussion forum where users can post questions, in a logged-in area, to other users. The ability to ask questions, to engage in discussion and debate with other colleagues from other disciplines and clinical settings is useful in a cross-cutting area of clinical practice. Participants had said that much of the useful information they had found and which helped in their clinical practice was through networking, and social media such as Twitter, but that finding information and guidance is often sporadic, un co-ordinated and ‘not all in one place’.

This section of the site will also be where users can upload resources which are useful to others. Examples include recorded talks, conference papers and journal articles, training courses, policies and procedures, where authors have made content publicly available.

Section 7 – Links between mental and physical health

This section will provide information from service users and carers about the links between mental and physical health and their experiences in seeking health care support. It aims to help users understand the impact of mental health on physical health and vice versa. It will again use film and visual images to tell patient and carer stories and build user understanding and confidence when dealing with this patient group in a more holistic, supportive way. It will include links to relevant national policy and strategy from NHS England, Public Health England and the Royal College of Psychiatrists. It will also include links to service innovation films, campaigns and other good practice from across the UK and internationally.

Section 8 – What does good PEOLC for people with SMI look like? – A proposed care pathway

No current care pathway exists for people with SMI and terminal conditions. Part of the recommendations from this study will include the development of a care pathway or a set of standards and expectations of care. This section will include a suggested model care pathway, highlighting key referral points for different professionals and services. There will always be local variation, depending on service provision and the organisation of healthcare services; however, a suggested model of good practice will be included for users to consider.

This will function as an interactive care journey, where service users can click on different key points in the care journey and see what is appropriate or possible at each stage. The patients and carers interviewed earlier in the co-design process referred to long gaps, with no support between point of diagnosis and the last weeks of life. This section will provide guidance as to which referrals to services might be appropriate at different points, for clinical staff to consider.

Section 9 – Resources

This section will provide links to key policy, strategy and guidance from central government, NHS England, Department of Health and key charities such as, Hospice UK, Marie Cure and MIND, who produce relevant policy level information. It will also include information about Mental Capacity, Deprivation of Liberty, Lasting Power of Attorney and links to external resources for end of life care planning such as making a will etc. See Appendix 6 for further suggestions generated by workshop participants. Relevant links to other website and resources will be included.

An interactive Glossary where users can access a quick and easy way to look up key terms which arise across mental health and palliative and end of life care. It will be presented in an interactive format, a definition provided and hyperlinks will be used to signpost users to link to other parts of the web-based resource. For example, if someone looks up what Advanced Care Planning means, an option to go to Section 4 Developing My Skills and to Section 9 Resources will be offered to encourage engagement with the different areas of the resource. A link to previously asked questions in the interactive Q and A section will also be provided to encourage users to engage with the interactive community aspect of the resource.

6.4.2 Resource Evaluation

There are two aspects to evaluating web-based resources; 1) the usability of the website and 2) the impact of the content, in this case the impact on the knowledge, skills, confidence and attitude change of clinical staff in relation to their clinical practice.

The evaluation of usability would be carried out throughout the development of the resource and has already begun with the paper prototyping stages. Muniz (2017) highlights that paper prototyping can form the early stages of usability, because it causes users to have to think about the content in the form of a webpage, considering links between content and how content is presented. In a co-design process, usability testing can be integrated into the development process from the start. Future development of this resource will include further rounds of co-design which participants, including designers, will be involved in. Other stakeholder groups can also be invited to test the functionality of the website to ensure that usability is tested with groups not involved in the development of the resource, for example test groups of clinicians in different settings. It is important that usability is not tested at the end of the process, but embedded throughout, in line with iterative co-design principles (Rubin and Chisnell 2008).

There are multiple models of usability testing. Tullis and Stetson (2004) carried out a review of models of web usability testing and found the simplest model (a 10-question approach), the System Usability Scale (SUS), to be the most effective and could be used to test the functionality of the web resource as it is developed. When involving clinical staff in the co-design of a web-resource it is important to make usability testing straightforward and not time consuming. Clinical participants, like service users, will most

often not be experienced in website development, so adopting a simple, but effective approach is important.

Evaluating the impact of the resource on clinicians and clinical practice is more complex and can only be carried once the web resource has been, developed, tested, piloted and launched. Simple user-centred evaluative methods such as quizzes and tests are commonly included in web-based learning to allow users to assess quickly the knowledge they have acquired; however, this does not test whether attitudes have been changed, whether learning impacts on clinical practice or how long knowledge is retained (Chumley-Jones, Dobbie and Alford 2002, Maloney et al. 2013, Reeves et al. 2017).

Much has been written about how best to evaluate web-based learning resources and a recent review of evaluation approaches (Nicoll et al. 2018) highlighted the need for continued development of effective evaluation models for measuring impact of resources for healthcare professionals. Nicoll et al. (2018) found that evaluation models which combine pre and post-test knowledge score testing with learner satisfaction surveys were the most common approaches and highlight Pickering and Joynes (2016) model as a holistic approach, appropriate for healthcare learning. This approach can be adapted to the clinical setting and resource function and would be appropriate for evaluating impact. It could be used over a period of time to evaluate the ongoing impact. Further consideration of how to capture improvements in patient and carer experience will also be required, in the next stage of development, but fell outside the scope of this study.

The four stage model evaluates impact from the development phase through learner impact to institutional impact (See Table 22).

Table 22 Pickering and Joynes Model of evaluation (2016)

Levels	Derived from	Measured by	Notes relevant to this study
Level 0 – Primary evaluation of need	Evaluation, feedback, assessment/audit, identified need	Perceived shortfall in knowledge, existing resource, feedback	Scoping literature review, clinical observations, earlier study of clinician's views, patient and carer interviews
Development phase (not an integral part of the evaluation model)	A collaboration of all stakeholders is required, to ensure resource is appropriate, relevant and legitimate. (Including initial decision to develop technology enabled solution as most appropriate solution)		Co-design participants involved in development of resource, scoping of content and format, identifying stakeholder needs
Level 1 – **1a) Learner Satisfaction** **1b) Learner Gain**	1a) Likert-scale questionnaire, focus groups 1b) Pre and post-test measures	1a) Level of satisfaction with resource 1b) Degree of equity in learner gain between resource and pre-existing learning resources	Specific questionnaires would need to be developed to ask questions specific to aim of resource i.e. how easy was it to access the resource when you needed it? How useful were the different elements of the resource – patient films, role plays, links to other organisations and resources, interactive discussion forum etc.
Level 2 – Learner Impact	Likert-scale questionnaire, focus group, usage metrics, assessment data	Influence of resource on outcomes for learners	Important to ask users about how the resource impacted upon their feelings towards patient group, to measure attitude change, could be done through focus groups and questionnaires but also by looking at referral rates, clinical notes
Level 3 – Institutional Impact	Return on investment analysis including multiple measures of impact	Measuring impact on a range of stakeholders	Important not just to focus on financial aspects, but on quality of care, patient and carer feedback, staff feedback, reduction in complaints, partner organisation feedback etc.

6.4.3 Next stages of development

As an exploratory study, this research project sought to develop the concept, content and format of a clinical resource to improve the knowledge, skills and confidence of clinicians working with people with SMI and terminal conditions. The participatory, co-design methods adopted involved clinicians, patients and carers alongside researchers in the initial stages of resource development.

The next stages, which form part of the post-doctoral phase, will be to undertake further co-design, including web-designers, to develop the resource into a working web-based, interactive learning resource for piloting with staff, further development and evaluation.

6.5 Chapter Summary

This chapter has presented the findings of the workshop stage of the co-design process. The features of the prototype resource have been identified and presented, and issues surrounding evaluation have been discussed. The next chapter presents the wider significance of these findings, the research questions are answered, limitations of the study and reflections on the methodological choices are discussed.

Chapter 7 Discussion

7.1 Introduction

This chapter will address the three research questions explored in this thesis:

- What are the views and experiences of patients with severe mental illness, and informal care network members, of care and treatment when diagnosed with a terminal condition?
- How does co-design support the creation of a clinical education/information resource? What are the key features of such a resource?
- Can the use of visual and creative methods enhance the impact of a clinical education/information resource?

Subsequently, reflections on research design and methodology, quality issues and limitations of the study are discussed. Additionally, personal reflections on the impact of the research journey on the researcher and considerations of the role of the insider researcher are also discussed, to provide contextuality to the chosen approaches. These two sections are written in the first person to enhance the reflective voice. The chapter concludes by identifying the novel contributions of the thesis.

Little was known about the views and experiences of people with both SMI and a terminal condition from their own viewpoints (Donald and Stadjuhar 2019, Jerwood 2016). Only two studies within the published literature (Foti et al. 2005; Sweers et al. 2013) explored the views of people with SMI on their palliative and end of life needs, but these patients did not have a terminal condition. Current policy has encouraged a focus on improving the physical health needs of people with mental illness, but does not consider the end of life, death or dying. The barriers to PEOLC have been documented in the relatively small pool of published literature reviewed for a previous study (Jerwood 2016) and in a recent paper by Donald and Stajduhar (2019). However, this has largely been through the eyes of clinical staff and researchers. This study presents the first account from patients, and their carers, who have both SMI and a terminal condition. In addition, the published literature focuses largely on describing barriers to care, rather than exploring or developing possible improvements. This study also presents the first concept and content of a co-designed resource which aims to improve care.

7.1.1 Aims of the Study:

The overarching aims of the study were to:

- Gain an understanding of the views and experiences of patients with severe mental illness (SMI) and informal care network members on their palliative and end of life care needs and experiences of receiving care.
- Apply this understanding to the development of the concept and content of a co-designed education/information resource which aims to improve clinical practice.
- Contribute to the development of co-design methodologies and the analysis of co-design data.

Having presented the findings from each stage of the study in Chapters 5 and 6, the significant findings will now be critically discussed with wider current literature drawn upon. The discussion will be firstly structured around answering each research question.

7.2 Understanding the views and experiences of patients and carers

The first stage of the co-design process was a series of interviews with a group of patients and carers. The aim of the interviews was to explore the views and experiences of the patients and their care networks, to gather data to develop the next stage of the co-design of the resource. The previous research findings, which explored clinicians views, and the literature review findings, were also used to inform the workshop stage. As reported in the findings, interview participants were asked about their experiences in mental health, primary, acute and mental health care services, their views about their palliative and end of life care needs and their expectations of care. In addition, interview participants were asked about how they felt care could be improved.

Overall, patient and carer interviews were characterised by multiple experiences of poor care. From the way physical illness was detected and diagnosed, to how terminal prognoses were discussed, or sometimes avoided, and throughout the care journey until and beyond death. Both patients and carers recounted experiences of stigma and prejudice throughout their care journeys, of avoidant and hesitant communication from clinicians in all areas of healthcare, of being marginalised in decision-making and of poor communication and co-ordination of care. These accounts felt sad and frustrating to hear, highlighting multiple opportunities where patient and carer experiences could have been improved.

Through the analysis of these experiences, a conceptual framework was developed which presents four overarching themes (Figure 20). Although each was distinct, there were relationships between the themes. The hesitant and avoidant behaviour of clinical staff experienced by participants, stemmed from the stigmatised views of people with SMI staff held. These feelings of stigma and prejudice were strongly felt by participants. Both patient and carer participants experienced prejudice and were left feeling ignored and excluded from decision-making. The feeling of services 'stepping back' when they most needed to 'lean in', work together and connect, with each other and with patients and carers, stemmed from the negative experiences highlighted within the first three themes. The profound feelings of abandonment and confusion were troubling to hear and in stark contrast to the aims and ethos of both mental health and palliative and end of life care.

Each theme will now be discussed in turn and each finding will be explored in relation to the published literature and relevant policy.

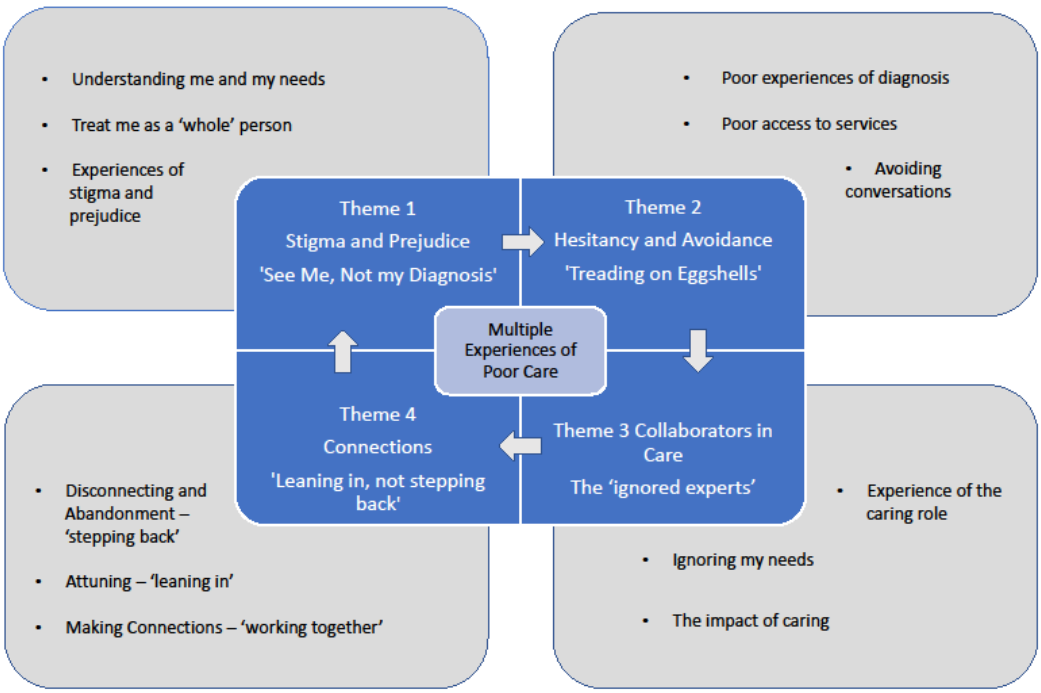


Figure 20 Interview Conceptual Framework

7.2.1 Stigma and Prejudice 'See Me not my Diagnosis'

Drawing on the findings, patients and carers had experienced multiple forms of stigma and prejudice. Since Goffman's conceptualisation of stigma in the 1960's (Goffman 1963) it has been well understood that certain groups in society are subject to discrimination and prejudice on a number of levels; intra-personal (self-stigma), interpersonal (relations with others) and structural (within laws, institutions, policies and systems). The patient participants interviewed had complex histories of mental ill health and had experienced stigma and prejudice in many areas of their lives, particularly in their relationships with healthcare providers. Repeated experiences of stigmatisation from others lead to stigmatisation within oneself and this was evident in the stories patients shared, particularly for Lorna and Colin, who both referred to times where they had hidden or minimised details of their mental health histories to avoid further stigmatisation and prejudice from healthcare providers.

Although many of the original groups in Goffman's study would now not be regarded as 'other' to the same degree (LGBT people, people with disabilities, people with addictions) and despite the existence of legislation to protect minority groups from discrimination, on a structural and individual level people from within these groups still experience discrimination in many areas of life. This is also the case for people with mental ill health. Despite a massive shift in understanding of mental illness since Goffman's conceptualisation in the 1960's, the participants in this study had experienced repeated and sustained discrimination in relation to their mental health diagnoses and histories. Knaak, Mantler and Szeto (2017) explored mental-illness related stigma in healthcare, concluding that there is still a prevalence of negative attitudes towards people with mental illness at all levels of healthcare. The experiences of participants in this study resonates with Knaak, Mantler and Szeto's (2017) findings and with the experiences of clinicians, who self-identified their own prejudices towards people with mental illness (Jerwood et al. 2018). The findings support the need for resources and interventions to be developed which challenge stigma and negative attitudes within clinical staff.

However, in addition, the participants experienced an additional layer of stigmatization once they became physically unwell, and again when they received a terminal diagnosis. Mental health services' inadequate response to physical health has been well documented and has led to a recent Government focus on improving the health inequalities of people with mental illnesses (Department of Health, Nursing, Midwifery and Allied Health Professions Policy Unit 2016, NHS England 2018, ReThink Mental

Illness 2012, Royal College of Psychiatrists, 2013). Despite this, participants experiences were characterised by delayed diagnosis, feeling 'fobbed off' and abandoned when they became physically unwell, which escalated further when they received terminal diagnoses. Participants wanted to be seen as 'whole' people and receive more integrated, better co-ordinated care. Stajduhar et al. (2019) identified the 'silo-ing' of healthcare roles and responsibilities leading to 'cracks' within which structurally vulnerable groups fall. Participant's experiences echoed this concept and it seemed that the professional silos in which professionals are trained and the way mental and physical health services are separately commissioned, exacerbated the feeling of 'separation' which participants felt. The silo-ed healthcare system also creates a complex system which vulnerable patient groups and their carers have to navigate, which impacts on access to PEOLC. However, participants were realistic about the need for specialisms and expertise in different areas of health but highlighted the poor connections between services and the need for all clinical staff to have a greater awareness of both mental health issues and palliative and end of life care issues.

People with SMI have particular challenges with regard to the separation of mental and physical healthcare which can leave them feeling disconnected. For someone with SMI who experienced psychosis, for example, this fragmenting of the self is unhelpful (Dixon, Holoshitz and Nossel 2016). Disconnecting and not seeing the different aspects of a person may echo aspects of the illness the person has been living with for a long time. Similarly, for people with personality disorder diagnosis, who may find attachments difficult, the splitting off of parts of themselves and the need to interact with lots of different care teams can be challenging and complex and lead to 'splitting' between teams (Feely et al. 2013).

It is interesting to consider again Goffman's work on stigma in regard to the separation into parts which patients can sometimes experience and which Jordan highlighted. If stigmatised views are underpinned by fear, then a fear-based response to a problem might be to break it down into parts which can be addressed or solved. Separating someone into a series of different diagnoses and conditions, all dealt with by different teams, might be a way of avoiding being confronted by the 'whole' person, which may feel overwhelming. However, the risk is that each team or health care professional involved only looks at 'their bit' and assumes others are addressing everything else (Simpkin and Schwartzstein 2016; Stajduhar et al. 2019). Patient participants experience was that this led to them falling between service gaps, feeling abandoned and invisible.

Patient participants recognised in themselves that their past experiences of being stigmatised, with regard to their mental health, impacted upon their ability to engage with services or work within the boundaries which services operate. For example, Stephen and Jordan talked about times where they felt unable to attend appointments or where they knew they were behaving in a problematic way. Their experience was of services which couldn't be flexible to meet their needs. The feeling of avoidance which patients described, when not attending appointments or not fully disclosing their mental health conditions, was mirrored in their experience of the approach of clinical staff. Participants found clinicians both hesitant and avoidant regarding discussions about their mental health needs and their palliative and end of life care needs. Interestingly, in the clinician study (Jerwood et al. 2018) clinical staff were apologetic, almost secretive, about when they had been flexible to meet a patient with SMI's needs, referring to it as 'breaking the rules' rather than seeing it as flexible, patient-centred care. Undoubtedly, people with SMI present additional challenges and have additional needs to patients without mental health difficulties, but clinical staff need to feel able to provide flexible, patient-centred care to people who face barriers when accessing services. The lack of confidence, sometimes fear, that clinicians feel when encountering people with SMI does not help them to feel autonomous or creative in their clinical practice.

The continued stigmatisation of mental illness has implications for clinical practice. For example, non-mental health clinicians require on-going learning and development opportunities to ensure they create dialogues with patients which enable patients to be open and talk about their mental health needs. Equally, mental health clinicians require similar learning and development opportunities to consider the physical healthcare needs of their patients. Likewise, they also require better understanding of the palliative and end of life care system, so that when terminal illnesses are diagnosed and PEOLC is needed, they are better able to help their patients access services and understand their role in supporting patients with terminal illnesses. However, there are currently no specific resources, training courses or interventions aimed specifically at clinicians working with this patient group. There is a lack of understanding of these patients needs across all areas of healthcare and the findings of this study highlight where, and how, patient and carer experiences can be improved. The themes within the interviews supported the literature review findings and recent published evidence which called for interventions which develop partnerships, involve patients and develop clinical confidence of staff (Butler and O'Brien 2018; Donald and Stajduhar 2019; Jerwood 2016; Shalev et al. 2017).

7.2.2 Hesitancy and Avoidance 'Treading on eggshells'

The patient participants in this thesis study experienced multiple occurrences of hesitancy and avoidance of conversations about diagnosis and prognosis, care planning and decision-making and end of life care preferences. Their experiences echoed those in the published literature. Donald and Stajduhar (2019) highlight the perception amongst healthcare professionals that people with SMI are not competent and lack capacity to make decisions about their care. McGrath and Forrester (2006) found that this presumption is made by healthcare staff solely on psychiatric diagnosis. However, including patients in the research and amplifying their voices, highlighted a challenge to this perception. Patient participants in this study were clear that they wanted to be involved in decision-making and conversations about their palliative and end of life care. The challenge lies in changing the views of healthcare staff that people with SMI are too vulnerable to participate in care planning and decision making. The findings within this theme again support the need for a resource which changes attitudes as well as providing knowledge and information.

The previous study by Jerwood et al. (2018) found that mental health and palliative care clinicians felt under-confident in talking to patients with SMI about their palliative and end of life care needs. Clinical staff fear de-stabilising, upsetting patients and triggering a decline in patients mental health. The findings of this study challenge this fear and present a counter perspective. Patients said that it was more frightening to be avoided and experience clinical staff 'treading on eggshells' which left them feeling further stigmatized.

The perception of people with SMI as weak, vulnerable, unstable, fragile and unpredictable is still powerful in contemporary society. Both Goffman's theory of stigma (Goffman 1963) and Stockwell's theory of the Unpopular Patient (Stockwell 1972) feel outdated, particularly when considering the language used to describe minority groups, however, the underlying prejudices described in these studies are echoed throughout the patient and carer interviews and in healthcare practice, even within mental health services. Baker and Stickley (2012) challenge Goffman's theory that those who work closely with the stigmatized group are able to avoid stigmatizing behaviour. The patient experience characterised in these interviews supports this challenge. Some of the most profound avoidance came from mental health services. Patients and carers both shared very recent experiences of poor response from mental health services to both physical ill health generally, but particularly to terminal and life-limiting diagnosis. Lorna's

experience following being told she had an incurable blood cancer, and possibly a few years life expectancy was to be discharged from mental health services. John also experienced a feeling of avoidance from his CPN who had no contact with him once he began to access hospice services for day care and respite. At times in participant's lives where they needed mental health support, it was not there. Stockwell's theory of the Unpopular Patient (1973) further highlights that people with mental illnesses form part of the cohort of unpopular patients who healthcare staff found it difficult to care for and whom they would avoid trying to care for. Whilst Stockwell was published in 1973, some of the findings in this thesis study sadly imply little has changed. Indeed, palliative care staff, who typically have little or no mental health training (Donald and Stadjuhar 2019), highlighted their own self-awareness in relation to their avoidance of mental illness and a belief they would have little or nothing to offer someone with a mental health diagnosis (Jerwood et al. 2018). Knaak, Mantler and Szeto 2017 (2017) conceptualise this as 'therapeutic pessimism'. Patient participants were aware of this belief and attributed it to clinician's fear and prejudice towards them, as people with SMI, and it echoes past experiences of poor care they have experienced. The hesitancy, which may stem from fear and lack of confidence in staff, was experienced as avoidance and prejudice by patient participants. These were worrying issues found in this study, which were at odds with the shared, patient-centred, ethos of both mental health and PEOLC services identified in the literature review (Section 3.4.1.1 Stakeholder Inclusion and Equity).

The avoidance of conversations about care planning not only impacted upon patient experience of diagnosis but also on their ability to access services. As a group of patients who often have limited or no care networks, clinical staff are the key conduit to accessing PEOPLC services. In addition to the link between the fear in clinical staff of upsetting or destabilising patients, and the avoidance of conversations about PEOLC needs, there is a connection between the lack of knowledge and understanding of PEOLC in mental health staff, which contributes to poor referral into PEOLC services. The benefits of early referral to palliative care for the general population have been highlighted in the literature (Hackett et al. 2018; Wadhwa 2018) and the additional benefits of PEOLC for people with SMI, who may have limited support and resources, have been highlighted in several reviews (Donald and Stajduhar 2019; Jerwood 2016; Mental Health Foundation 2008; Woods 2008). However, the lack of progress towards improving PEOLC for people with SMI has been highlighted as recently as Donald and Stajduhar's review (2019). Improvement will require both a deepening of the knowledge and understanding of clinical staff and a challenge and change in attitude towards people with mental illnesses.

7.2.3 Collaborators in Care ‘The ignored experts’

Carers experienced a profound paradox in their role, that of burden and exclusion, which is conceptualised as ‘the ignored experts’. UK policy regarding the role of carers has increased over recent years and has highlighted care burden and the support needs of carers (Bradley 2015; Carers-UK 2017; Department of Health and Social Care 2018). The importance of family relationships and carers views have been highlighted in both mental health and palliative and end of life care policy and strategy (Department of Health 2008; Department of Health and Social Care 2018; National Institute for Health and Care Excellence 2014; National Palliative and End of Life Care Partnership 2015). However, the paradox experienced by the carers interviewed has not been previously identified at a policy level. Carers had often occupied the caring role for many years and described the breadth and depth of their caring role with a person with a mental illness. The diagnosis of a terminal condition added to the care burden and the caring role intensified. Carers described feeling an expectation that they would be seen as experts in the person they were caring for, that person’s care needs, the health care system and its complexities, what services could be accessed and when. Carer participants had also made large personal sacrifices to continue the caring role; giving up employment, modifying their homes and putting their own physical health needs on hold. However, they also had poor experiences and suffered similar feelings of abandonment to patients. Their experience of trying to access support, guidance, information and involvement in care decisions was ignored, or subject to the same hesitancy and avoidance experienced by patients.

Positive experiences were reported by one carer who had support from a multi-disciplinary team with a range of professionals within it. The nature of her husband’s condition meant he was cared for by a particular condition-specific team where understanding of palliative and end of life care was embedded. Her experience was of professionals who were able to offer appropriate information at appropriate times because they had understanding of both mental health needs and PEOLC services and were more willing to have conversations about death and dying. This is interesting to consider when thinking about structures and silo working which has been identified as a barrier to care (Butler and O'Brien 2018; Donald and Stajduhar 2019; Jerwood et al. 2018; Relyea et al. 2019; Stajduhar et al. 2019). Whilst specialisms are necessary and inherent in healthcare, the connection between specialisms can be improved and have a positive impact on patient and carer experiences.

Carers experienced stigma by association, often experiencing similar forms of discrimination to patients. Carer participants talked about experiences of clinical staff rolling their eyes, being ignored or treated as though they were 'fussing'. Carer participants recalled experiences of clinicians fobbing them off and one patient participant commented on this, saying he had watch carers be treated badly, in the same way as patients. Goffman (1963) highlights that stigma can be experienced not only by the person or group seen as different, but also by those associated with them (including carers, family members and professionals). The negative impact of stigma by association places additional burden on carers and should be challenged in the same way as direct discrimination (Phillips and Benoit 2013). Sadly, carers experiences are similarly excluded from previous research and the wider literature regarding SMI and PEOLC and these findings highlight unmet carer needs which could be better understood by clinicians, through inclusion in an improvement-focused resource.

The interviews with carers were characterised by a feeling of wanting to improve care for others and insights into how improvements could be made, illustrated by where things had gone wrong or worked well in their experiences. Sometimes the carer role is that of an observer, looking in on a situation from a step removed. This can lead to being able to see things and make connections that the patient or clinician may not be able to see or articulate (Fadden, Shooter and Holsgrove 2005, Lavoie 2018). Overall, carer participants experience was characterised by feelings of frustration and weariness. The demands of the caring role combined with the frustrations of being ignored, or indeed stigmatized themselves, placed a great burden on the carers interviewed. Their insight into the barriers to care and expertise on the PEOLC needs of those they cared for were important in the development of the resource because they were often trying to navigate complex, unclear systems and were able to voice their frustration in a way that sometimes people with SMI find difficult.

7.2.4 Connections 'Leaning in, not stepping back'

The fourth theme conceptualises patient and carer experiences through connections. Poor care experiences were linked to feelings of disconnection or abandonment. Conversely, positive care experiences, including suggestions for how care could be improved, centred on making connections and attuning to patient and carer needs. One patient described this as 'leaning in and not stepping back'.

This theme highlights where care can be improved in terms of better access to specialist PEOLC, better provision of PEOLC by non-specialists services including mental health services and better partnership working between all parts of health and social care. Most importantly though, it highlights where individual clinical staff can improve the experiences of people with SMI and terminal conditions through their own approach to clinical practice.

Patients with SMI bring with them histories of rejection, exclusion and abandonment. For the patient participants in this study and to some extent their carers, being diagnosed with a physical condition, later becoming a terminal diagnosis, triggered a new wave of abandonment and rejection. Abandonment was predominantly by mental health services. The findings highlighted a negative response to physical, but particularly terminal, health conditions with patients being unsupported by mental health professionals with regard to their physical ill health and even being discharged from mental health services all together at a time when support was most needed. Feelings of exclusion came from palliative and end of life care services with patients feeling as though their mental health needs would not be understood or supported. This echoed previous findings where PEOLC clinicians had highlighted their own perception that they would not be able to support the mental health needs of patients with SMI (Jerwood 2016).

The findings highlight multiple occurrences of patients experiencing services and clinical staff ‘stepping back’. Within mental health, the recovery agenda is a driving force (Davidson 2005; Ramon, Healy and Renouf 2007; Slade et al. 2014) and one of the unintended consequences of a focus on recovery, and some of the misperceptions of what that means, is that patients who are terminally ill are viewed as not being able to recover, therefore mental health services withdraw support. This withdrawal of support often comes at a time where a patient most needs advocacy (to access new services such as PEOLC) and mental health support with the added psychological pressure of a terminal diagnosis. The ‘stepping back’ by mental health services appeared to stem from a perception that they have little to offer in providing or brokering palliative and end of life care. Improving understanding of PEOLC and roles and responsibilities of different services forms part of the recommendations of this study.

Interestingly, disconnection between patients and services led to a mismatch between what patients wanted and felt was important and what clinical staff believed was possible or important. This echoes Springham and Robert’s work in acute in-patient services

(Springham and Robert 2015). Whilst a prevalent clinician perception within the published literature is a that people with SMI are too fragile or lack capacity to participate in decisions about their care (Duckart et al. 2010; Geppert, Rabjohn and Vlaskovits 2011; Mental Health Foundation 2008; Woods et al. 2008), when asked, patient participants in this study were emphatic about both their ability and their desire to be involved in decision making and care planning. Patient and carer participants experienced clinical staff as hesitant and avoidant around them, echoing Bates and Stickley's (2012) observation that risk-averse practice in mental health services perpetuates stigma. The experiences of participants would indicate that this is also true within palliative and end of life care services further supporting the need to design a resource which develops clinician confidence.

The disconnection and abandonment which patients and carers experienced was exacerbated by poor care co-ordination and inconsistencies in care. The feeling of professionals stepping back at a time of extreme distress and vulnerability was powerful throughout the interviews. What participants identified that they needed was for the professionals around them to be able to be more present, to attune to them and to be able to 'lean in'. The positive experiences of care captured within the interviews related to moments where clinical staff were able to say the right thing at the right time, to bring up a subject or share information at the right moment for the patient. To do this requires clinicians to be able to both attune to their patient's needs and to be able to tolerate uncertainty.

In modern healthcare, uncertainty has generally been suppressed or not tolerated by both clinical staff and by patients. Simpkin and Schwartzstein (2016) explore the nature of uncertainty in healthcare and suggest that the focus on definitive diagnosis and the notion of the clinician as expert leads to fear and intolerance of uncertain situations, causing fear in the clinician. When clinicians experience fear, it is impossible to retain compassion and curiosity. In relation to the 6 C's in nursing (Care, Compassion, Competence, Communication, Courage and Commitment), Price-Dowd (2017) called for a 7th C - Curiosity. The ability to 'lean in' relies on professional curiosity as well as tolerance of the uncertainty of not knowing. Linking this directly to the findings of this study, patient participants wanted to be asked questions, to be able to share their fears, their views and their expertise with clinical staff, but found clinicians unwilling. Clinician participants felt a pressure to know, to get things right and were fearful of saying the 'wrong' thing.

The development of any resource needed to address these issues, not just provide more information or knowledge, but to help clinicians view their practice and this group of patients, and their carers, differently. It needed to address internal changes in clinical staff but also to bring clinical staff together. Stadjuhar et al. (2019) highlight the importance of building partnerships between agencies, so expertise can be shared and to bridge the cracks between which structurally vulnerable patients fall. The experiences of the participants in this study certainly echo this and the need to build better partnerships between specialist and non-specialist palliative care services, between mental and physical healthcare services, including palliative and end of life care, is crucial to the improvement of care experiences of people with SMI and terminal illnesses.

7.2.5 Interview Conclusions

The themes developed in the analysis of the interview findings are distinct but interconnected. Patient participants highlighted that they are not as vulnerable as clinicians think, that they are resilient and want to participate in the planning and delivery of their care. Patients and carers wanted clinicians to be able to sit alongside them, ask questions, find out, to plan care together.

This study is the first to include patients and carers with both SMI and a terminal condition. By including these interviews in the study, a new perspective about patients views and experiences is presented as a contribution to the published evidence. Previous research has shied away from including this group of patients and their carers, policy has not included their needs or indeed their views or experiences. However, by capturing these experiences, these voices have been able to be shared and also to contribute to the development of a resource which aims to improve care.

Despite legislative and societal changes to understanding of both mental illness and to death and dying, these patient and carer participants experiences were characterised by multi-layered stigma and prejudice. It is evident from the study findings that there is still significant improvement required in the quality of care people with SMI and terminal conditions receive in mental health services and in palliative and end of life care. This stage of the co-design process was important because it explored patient and carer experiences which then informed the development of the resource.

7.2.6 How interview data informed workshop design

Reflections on the research design are discussed again later in this chapter (Section 7.5.1) but it is important to describe how the workshop design was informed by the interview data as part of the co-design process. Through the interviews the researcher was able to gain insight into the poor experiences of patients and carers. The interview data generated a series of questions for the researcher, reflected in field notes:

> *These interviews raise a series of questions; How do we 'lean' in? How do we avoid stepping back? How can we work better together? How can we stop treading on eggshells? How is stigma/stigmatized views best challenged in a supportive way?*
>
> *What do clinical staff need? How does this differ across clinical specialism or setting? How can fear be overcome, not just through reiterating principals of equality? How can we feel safe and overcome fear and sit with uncertainty? And remain curious?*

The structure and framing of the questions and activities carried out in the workshops was directly informed by the analysis of the interview data and the questions it generated. A short presentation at the start of the first workshop included a summary of the indicative themes from the patient and carer interviews, along with the summary of the literature and the clinician study, to provide context to the workshop tasks. For example, the first round workshops asked participants to consider what types of content would challenge stigma, and how best this could be conveyed. This led to conversations developing between participants about how best to tell patient stories, and to see beyond diagnostic labels.

When designing the tasks and activities for the second workshops the interview findings were again considered, along with the analysis of the first round of workshops. The groups had identified the proposed content and format of the resource in the first set of workshops. Then in the second set they began to consider the prioritisation of different types of content and the best format for each type of content. and further to design some of the specific elements of the resource. The themes within the interviews were reflected in the workshop discussions through overlapping participation by some participants, but also by sharing quotes and themes with the workshop groups.

On reflection, the presence of more of the interview participants in the workshops stages would have added even more richness to the workshop discussions and developments. However, there was some overlapping attendance with those who felt well enough to participate. Presenting a summary of the key themes of the interviews, from the initial analysis, at the start of the workshops went some way to mitigate this and the themes in the interviews were echoed throughout the discussions and within the content and format of the proposed resource.

Adopting a co-design process which included interviews and workshops, enabled the researcher to draw on the factors that the interview participants considered were most important to be included in the resource and influenced the design of the workshops.

7.3 Exploring the use of Co-design to develop a resource

The key features of the resource are presented at the end of Chapter 6 (Co-design Findings – Workshops), and their significance is critically discussed below. The application of a co-design approach in the development of the resource will be discussed in the context of relevant theory. In addition, this section will discuss what is known about how healthcare professionals learn and develop confidence through attitude change. Bandura's Theory of Self-Efficacy (1977) provides a theoretical underpinning to the nature of the resource developed.

7.3.1 Key features of the resource developed through the co-design process and their relationship to theory

In line with the constructivist and participatory philosophical positions which informed the research design, the theoretical underpinning of the co-designed resource assumes knowledge to be generated by the process of inquiry. Knowledge is not just something which can be passed from teacher to learner, knowledge can be generated by learners working in collaboration and interaction.

Bandura's Theory of Self Efficacy (1977) offers a helpful framework to consider the content and format of the resource and more recent literature regarding the efficacy of web-based learning (Antheunis, Tates and Nieboer 2013; CERD 2008; Chumley-Jones, Dobbie and Alford 2002; Garrett et al. 2016; Reeves et al. 2017) informed reflections upon the key features of the proposed resource. Self-efficacy concerns a person's belief of their own capability to perform a certain task. Bandura identified that four elements contribute to a person's feeling of self-efficacy;

1) performance accomplishments/attainment, 2) vicarious experience, 3) verbal persuasion and 4) physiological state. Performance accomplishment and vicarious experience are identified as most influential, but verbal persuasion and physiological state play an important role (Bandura 1977).

It is interesting to consider each of these elements in relation to the key features of the resource developed through the co-design process. Participants were asked to think about both format and content of the resource early on in the co-design process. It had already been established in previous literature that there are significant barriers to accessing and providing PEOLC for people with SMI (Donald and Stajduhar 2019; Duckart et al. 2010; Feely et al. 2013; Jerwood et al. 2018; Mental Health Foundation 2008; Shalev et al. 2017; Terpstra and Terpstra 2012; Terpstra, Williamson and Terpstra 2014). Themes within the patient and carer interviews had echoed many of the clinicians views of barriers to care and highlighted their own repeated experiences of poor care. Clinician lack of confidence had been identified as a significant issue, underpinned by fear and stigma towards the patient group. So a shared aim of improving clinician confidence, skills and knowledge was identified and informed the workshops. Low confidence and a lack of self-efficacy interlink in this situation. As presented in the findings, clinician's perceptions of their own capability to provide good PEOLC to people with SMI was low. So a key feature of the resource needed to be building confidence, inspiring curiosity and reducing fear, thus increasing feelings of self-efficacy.

As presented is Chapter 6 (Co-design Findings – Workshops), the proposed resource can be best defined as an interactive, online educational and knowledge repository. It uses a range of methods to provide relevant content identified by participants, for example:

- Film will be used to tell patient stories, show role plays between clinicians and patients, show conversations between patients and clinicians and different professionals in conversation with each other.
- Information and guidance will be included, links to other websites, policy and legislation, good practice and existing resources are provided.
- Short myth-busting films and over-arching messages about mental illness, death and dying, palliative and end of life care will be included.
- Exposure to patients with SMI and terminal conditions through film, personal accounts and narratives will be incorporated to different sections of the resource.

- Interactive sections, a discussion forum and question and answer sections will encourage users to ask questions of the user community.
- More formal learning will be included in links to short online courses, online journal and workbooks for staff. Staff can test their knowledge and skills and share examples of good practice, celebrating success and improved confidence.

These different features of the resource link to Bandura's four elements of self-efficacy.

1) Performance accomplishments/attainment – Users can assess their own improvements in performance through engaging with the online reflective journal to think about changes in their practice, e.g. improved confidence in starting a conversation about advanced care planning or helping a patient access a hospice service and also through completing online learning provided in the links to existing courses section. In addition, being able to read and see other examples of good practice shared by other users, users could feel more able to share examples from their own practice, developing the interactions and shared learning opportunities that the interactive aspects of the resource offer (Soubhi et al. 2010; Wenger, McDermott and Snyder 2002; Wenger 1999). As demonstrated in the workshops, participants did not always feel what they were doing was good practice, but in talking with others, they found they were more confident than they had previously realised, this learning opportunity could be supported through the interactive sections of the resource.
2) Vicarious experience - the observation of successful (and unsuccessful) performance in others is identified as an element of self-efficacy. By watching other clinicians' role play, or discuss with each other, their approaches to starting difficult conversations, or raising sensitive issues, users can build feelings of confidence in how to approach situations. Reflections on when this occurred within the co-design workshops are discussed in the next section. However, it is interesting to note that participants were very keen to be able to observe others as a way of learning. The online nature of this resource and the use of film allow this to be available without time, geographical or clinical boundaries to a wider audience (Reeves et al. 2017).
3) Verbal persuasion – verbal persuasion is used widely in healthcare education but Bandura states that it is not as powerful in developing a feeling of self-efficacy as personal mastery (performance accomplishment/attainment) or through observing others (vicarious experience). However, the proposed resource

includes verbal persuasion as a method of delivery through the films of myth-busting examples and through links to existing resources which may draw on more traditional methods of learning (links to existing courses for example). Using patient made films adds to the impact of verbal persuasion by directly relating learning content to patient experience (Halpern and Humphreys 2016, Prosser 2011).

4) Physiological state – a comfortable physiological state is important in developing a feeling of self-efficacy. Feelings of fear or anxiety about clinical practice do not engender feelings of confidence, competence or self-efficacy in clinicians. Much of the resource is designed to alleviate feelings of fear and anxiety through reducing stigma. One of the components of stigma reduction has been identified as social contact (Knaak, Mantler and Szeto 2017). The co-design process offered this to participants, and they felt it was important to include though the use of patient and carer films in the resource. Participants identified that being able to see patients as people and not just labels or diagnosis was important in helping them to feel more confident and less fearful and that a web-based resource which uses patient and carer films would be a useful way to increase the potential audience and reach of the resource.

Much has been written about the learning styles of healthcare staff (Crannell and Witte 2012; Mashhood et al. 2017; McCrow, Yevchak and Lewis 2013; Nizami, Latif and Wajid 2017; Salehi 2007) building on the early work of learning theorists such as Kolb. Kolb (1985) identified that people do not learn in the same way and that people have different learning styles. There are multiple theories of learning styles (Biggs et al. 2001; Entwistle and Tait 1995; Felder and Silverman 1988; Honey and Mumford 1992; Kolb 1985; Schmeck et al. 1991) and each has a different model, but what unites them is that acknowledgement that people learn in different ways and that learning approaches need to address different styles through a variety of media (Cassidy 2004).

Healthcare roles incorporate a wide range of clinical disciplines across medicine, nursing and the allied health professions and the literature regarding learning styles is broad, focusing on specific professions and using a range of learning style models to assess. Health care staff have diverse learning needs and preferences (McCrow, Yevchack and Lewis 2014; Nizami, Latif and Wajid 2017) and require a variety of approaches to learning. The findings of the workshop stages supported the themes in the literature and

the learning resource proposed will take account of this through the variety of learning opportunities and media offered within the online format.

A key feature of the resource developed related to the format – a web-based learning platform. Early on in the co-design process, participants identified that to be useful, the resource needed to be accessed as and when it was needed. Clinician participants were clear that the combination of clinical pressures, time and funding mean that creating a face to face training course would create barriers to access. The discussions about content quickly led participants to conclude that the best way to present the types of content they were identifying, and to make sure the resource was as accessible as possible to a wide range of healthcare professionals involved in the care of people with SMI and terminal conditions, was to develop a web-based resource.

Web-based learning has been used within healthcare settings since the early 1990's (Chumley-Jones, Dobbie and Alford 2002). It is now widely accepted as a complimentary approach to traditional face-to-face education. More recent research has found web-based and e-learning approaches to be as effective as classroom learning and has other advantages such as reducing logistical barriers, offering tailor-made, point-of-care learning that meets the needs of a range of healthcare professionals from multiple practice settings (Maloney et al. 2013, Reeves et al. 2017). One of the criticisms of web-based learning is that it can isolate learners, however, developments in technology have enabled more experiential and interactive web-based learning to be developed which can mitigate against learner isolation (McLoughlin and Luca, 2002; Reeves et al. 2017). The findings from the workshop stage support the published literature highlighting the importance of easily accessible, interactive and online resources, which clinical staff wanted to be able to access in a clinical setting when it was required.

A scoping review of interprofessional online learning by Reeves et al. (2017) found that online learning is effective for improving a range of professional competencies including attitudes as well as knowledge, skills and behaviours. The review also highlighted that interprofessional online learning has the potential to develop collaborative competencies through use of discussion forums, message boards and 'question and answer' forums.

There are challenges to developing such as resource. The upfront costs of development, including making films and developing the new content aspects. In addition, such a resource would need to be moderated and kept up to date to ensure it was relevant and useful. Some of these issues have been highlighted earlier in the thesis (Chapter 6, Sections 6.4.1 Resource Evaluation and Section 6.4.2 Next stages of development).

However, issues such as where the resource might be hosted will need to be resolved early on in the development of the prototype for piloting. Participants raised the issue of where the site would be hosted and explored some of the pros and cons of different options. The advantages of hosting within an established site such as Hospice UK were discussed, but this automatically excludes an important cohort of users who don't work in the PEOLC world. Similarly, hosting via a mental health organisation would have similar exclusionary effect. The aim of the resource is to create something readily accessible in the clinical setting which can be accessed when it is needed. Participants were very clear that creating a training course which they attended for half a day or a day would not have the impact needed. It may be that the solution is to develop the resource as an independent web-based tool which can be signposted via organisational learning and development platforms. Some organisations already use this approach to link to external content or resources, making them available to clinical staff as part of organisational learning and development programmes. There are other challenges including bringing together existing resources, time and expertise to develop a site, gaining funding and external support. However, by sharing the findings of the research, the importance of addressing how PEOLC care can be improved for people with SMI has been highlighted and interest at a national policy level from NHS England and Health Education England, as well as with key PEOLC and mental health voluntary sector bodies has increased.

In line with the ethos of co-design methodologies, participants were encouraged to think broadly about what is needed and what the best solutions might be. They were encouraged to think outside of the usual boxes, not to be concerned by their own perceptions of what the limitations might be, and to focus on what they felt was lacking, what was needed and how it might best be developed. It is during the piloting stages that some of the challenges identified will need to be addressed.

In summary, the key features of the resource, key content and format priorities were presented in detail in Chapter 6 (Co-design Findings – Workshops). The key aspects of the proposed resource have been discussed in relation to Bandura's (1977) model of Self-Efficacy and in relation to theory regarding learning styles and online and e-learning. The challenges of developing such as resource have also been discussed. The next section addresses how co-design as a research method supported the development of the resource.

7.3.2 How co-design supported the development of the concept and content of a resource

As an overall approach, the co-design process supported the development of the resource in several ways which will be discussed in this section in the context of the wider co-design literature. The model of co-design used will be critically considered and the findings discussed in light of recent understanding of co-design, and broader co-creation, methods.

The literature review (Chapter 3) highlighted that one of the key opportunities of using co-creation methods was the potential for patient and carer participants, and other stakeholders, to be given greater equity with researchers. Co-design allows researchers to work *with* participants, rather than do *to* them. The New Economic Foundation (NEF 2013) developed an alternative to Arnstein's Ladder of Participation (1969). Arnstein's model has been widely used to understand differing levels of citizen participation in the context of power dynamics (Wheeler 2018). In their adaptation of the Arnstein model, the NEF have adopted contemporary language related to healthcare and design and distinguish 'Doing To' and 'Doing For' from 'Doing With'. 'Doing With' is presented in the model as the higher level of participation and emphasises the collaborative approach which the research design for this study aimed to achieve.

Consequently, drawing on the body of literature and as highlighted in Chapter 2 (Contextual Background) patients with SMI are often ignored and their views not valued (Mental Health Foundation 2008; Woods et al. 2008) by professionals (or researchers). The discussion between patient, carer and clinician participants in the workshop was therefore crucial in discussing this in a safe forum in order to shape the concepts for the resource. Creating equity amongst participants was identified in the literature review (Chapter 3) as an opportunity and a challenge of adopting co-design approaches (Cooper, Gillmore and Hogg 2016; Freeman et al. 2016; Gillard et al. 2010; Springham and Robert 2015). Ensuring that participants feel valued and equal to other participants, when bringing together patients and clinical staff of different levels, is difficult to achieve. Even amongst professionals, hierarchies exist and line management responsibilities can create inequity in workshop settings. However, the creative methods acted as a leveller between participants, disrupting traditional hierarchies. This is further explored in Section 7.4 (The Impact of Visual and Creative Methods) . The presence of patient and carer participants, although small in number, added an enormous amount to the discussion in

the workshops. Patient and carer participants were able to voice their experiences and bring to life the interview findings.

In addition to giving greater equity to patient and carer experience, co-design offered opportunity for clinician experiences and views to be validated as well. Particularly the frontline clinicians who attended who may not usually be involved in service development, but who are often tasked with implementing it. As Springham and Robert (2015) highlighted, involving those staff who will be responsible for implementation of a service development or those who will be the end user of a resource is important. They will have insight into what is needed and what will and will not work, in a different way to senior managers, external researchers or consultants. The researcher's role as an insider researcher is explored later in this chapter, but his role as a clinician and a researcher was important in facilitating the workshop discussions as he was able to relate to the participants' roles to some degree and had some understanding of the limitations and clinical issues they were raising.

As discussed in the Literature Review (Chapter 3) co-creation methods have been found to lead to a better 'end product', be that a service development or a new product or resource (Chambers et al. 2017; Davies et al. 2016; Lwembe et al. 2017; Meddings et al. 2014; Springham and Robert 2015). The involvement of the 'end user' as stakeholders in the co-design process is important and the range of participants in the workshops really highlighted how this works. It was visible to see how the range of participants added a richness to the data collected. The process of iterative rounds of data collection, with levels of analysis between, allowed the concept for the resource to emerge, and then grow and evolve. The 'paper prototyping' techniques allowed participants to work with the data they had generated in the earlier stages of the co-design process and to really work through how and what the concept for the resource should be and how it would meet their needs. A traditional consultation process would have collected lots of comments which would be then considered by the researcher or designer and either adopted or disregarded. However, the creative co-design process used allowed this process of development and refinement to take place by the participants themselves. This led to the 'end product' of the co-design process, the concept and content of a resource, to feel more embodied than a traditional consultation output. Studies by Hassan et al. (2017) and Street et al. (2007) informed the way the data is presented in Chapter 6 (Co-design Findings – Workshops).

Thirdly, co-design supported the development of the resource was in moving away from a traditional 'teacher to student', face to face, didactic learning to a more interactive, narrative based 'community of practice' informed approach (Wenger et al. 2002; Wenger 1999). Throughout the iterative process, participants discussed and worked out the content and format of the resource as a multi-disciplinary group from a variety of backgrounds. They generated their own answers to some of their own questions through engaging in the co-design process. In line with the participatory, constructivist principles which underpin the research, learners brought multiple perspectives and knowledge to the co-design process. The result is the concept and content of the interactive resource, co-designed by its stakeholders and end users, aiming to improve PEOLC for people with SMI. This has not previously been the focus or outcome of any clinical research.

The fourth area in which co-design supported the development of the resource is in some ways the most interesting as it was not highlighted within the literature. Participants experienced coming together, with patients, carers, and a wide range of clinicians within the co-design workshops. Although the aim of the workshops was to co-design a resource, the process also involved participants doing some of the things they were identifying as important to include in the resource. This included making relationships and building partnerships, sharing knowledge and expertise, role playing and role modelling how to have difficult conversations and sharing examples of best practice. It allowed clinical staff to hear patient and carer experiences of care, and it allowed clinical staff to hear the different experiences of different clinical specialisms. Participants were discussing the content and format of the resource and identifying what should be included based on what another participant had said – for example a palliative care consultant talked about how he approaches conversations about end of life care and a mental health nurse said it would be helpful for her to watch a role play of the conversation, or a film of the consultant talking with a patient. Participants also identified the potential to provide each other with training, to invite patients and carers to tell their stories and share their experiences. The co-design process adopted brought all these participants into the same workshop and the value of doing this was evident in the data collected. In addition, it highlighted clinical limitations, areas of development and gave participants a better understanding of each other's limitations and perspectives. In effect, the co-design process also offered opportunities to build relationships and for better partnership working, both of which were recommendations from the previous study. This was evident when two participants arranged a student placement and another arranged a shadowing opportunity. In addition, a carer participant agreed to go and speak at one

of the participant's team meeting. Co-design did not just offer benefit to the development of the concept of the resource, but also contributed to wider developments and better working relationships locally and contributed to the personal development of those that took part in research.

It is interesting to consider this in light of theories of reducing stigma. Stigma between clinicians and patients but also between different specialisms. The theory of 'social contact' between patients and clinicians as a means of reducing stigma was developed by Knaak, Modgill and Patten (2014) and further explored by Marazan (2016) and Agrawal et al. (2016). In stigma-reduction initiatives, social contact approaches typically involve patients with lived experience working with clinical staff in education or research settings. Co-design offers opportunities for this form of social contact when patients and carers can participate alongside clinical staff and researchers on a shared endeavour. Social contact has been shown to challenge stereotypes, challenge clinicians anxiety, heighten empathy, make personal connections and improve understanding (Knaak, Mantler and Szeto 2017). Co-design offered opportunities for social contact between all the different participant groups (patients, carers and staff) who often hold stigmatized views of each other and it appeared to offer opportunities for increased joint working.

7.3.2.1 A critique of the co-design model

The specific model of co-design adopted was tailored specifically for this research study, taking the complex needs of participants and the limitations of the PhD timeframe and resourcing into account. As discussed in Chapter 4 (Methodology), Holliday, Magee and Walker-Clarke (2015) developed an illustrative model of co-design as distinct from traditional linear design processes (see Figures 2 and 3 p. 88).

The model highlights the circular, iterative nature of co-design and its participatory origins, highlighting the involvement of all stakeholders in the design process, including designers, however a decision was taken not to involve designers in this stage of the study. The involvement of designers in the early stages of co-design has been debated within the published literature (Grönvall and Kyng 2013; Lindsay et al. 2012; Newell et al. 2006; Wherton et al. 2015). Arguably, designers should be involved throughout the co-design process as equal stakeholders with researchers, patients or other end users. However, two situations arise where designer involvement may be delayed or not appropriate. Firstly, if co-design workshops are taking place with vulnerable groups of stakeholders or in restricted locations such as secure settings (Springham and Robert 2015). Secondly, if it is unclear what is being designed, as in the case of this study. It

was only through the early stages of co-design that it became clear that the format of the end product would be web-based. The nature of the end product will inform the type of designer involvement.

In addition, resourcing of the co-design project may mean that designers are brought into the process at a certain point where funding for development has been obtained. It was not the intention of this study to involve a designer from the very start, due to the exploratory nature of the research questions, the vulnerability of participants and scope of the project. The intention is to take the concept forward into development as part of the post-doctoral phase of the research programme and it will be at this point that a web-designer will be included in the next round of co-design. There are outstanding questions to be resolved regarding the scope of the resource and where it will be hosted that will impact on the type of designers required.

The advantage in this case of not bringing a designer in early, was that the co-design participants were made up of beneficiaries (patients and carers) and end users (clinicians) and so the evolution of the resource was very user-led. However, the disadvantages of not including designers at the early stages are two-fold: time can be lost if co-design participants pursue impossible options or solutions and the researcher can end up acting as a facilitator of communication between the participants and designers, which can introduce a degree of researcher bias (Bergvall-Kåreborn et al. 2010; Grönvall and Kyng 2013).

The Holliday et al. model (2015) illustrated in Figure 3 (p.88) informed the individual co-design model developed for the research process. One of the strengths of co-creation approaches identified in the literature review is the flexibility of the approach to be tailored to each individual project (Fox et al. 2018). In healthcare settings, this allows researchers to develop, or even co-create, each approach and to take into account considerations such as, the nature of the questions, the issues or problems to be addressed, the stakeholders needs and limitations and the clinical setting. The Holliday et al. (2015) model was developed taking all of these constraints into account, whilst including the elements of iterative data collection and (re)analysis into the design.

The model supported the study design which aimed to include as wide a range of clinician, patient and carer participants as possible. Some participants in the workshops had two different ‘identities’ – staff members who were also carers, or staff members who were former service users for example. This was not anticipated but added a depth

of experience to the workshop stages and was accommodated by Holliday et al.'s model. Where the model does not convey the process of codesign is in not emphasising the circular nature of the process, implying only one 'round' of data collection or design. Whilst this distinguishes it from more traditional, linear, design approaches it does not account for the iterative, multiple rounds of data collection which occurs in a co-design process. Neither does it account for the early stages of pre-design, or co-defining what is being designed, implying designers can be included from the outset. For example, Ward et al. (2015) described a two round project where industry and designers are introduced after the initial stakeholder workshops. The Holliday et al. (2015) model does not emphasise the multiple cycles of co-design sufficiently.

In considering the model adopted and how useful it was for the research study, it is important to acknowledge the innovative nature of the research method. Co-creation methods, although adopted in clinically settings for several years now, are still relatively new and emerging. Even since the development of the research design used in this study, thinking about co-creation approaches has evolved. The Co-creating Welfare Project (Pearce et al. 2018) has developed a Co-Creation model to better describe the process of co-creation. The model describes a process of co-defining, co-designing and co-refining, which is useful in reflecting back on the research design adopted. The inclusion of co-defining and co-refining better illustrate the process adopted within this study. The co-defining of the project and the desire to co-refine with participants felt an important part of the process. It could be argued that the process of co-defining, co-designing and co-refining describes the stages of the research design adopted. The interviews and underpinning research can be understood as co-defining, the workshops as co-designing and the next stages of development as co-refining.

Co-creation, co-design and co-production models continue to evolve and develop and the terms continue to be used interchangeably as highlighted within the literature review themes (Section 3.4.2.1 Inconsistency of Methodological Approach). The literature review highlighted that one of the challenges of using co-creation is to ensure the key elements of it are not lost in the flexibility of the approach. The model of co-design used within this study retained the key participatory principles of, stakeholder-led design and iterative rounds of data collection and analysis.

7.4 The Impact of Visual and Creative Methods

The third and final research question related to the use of visual and creative methods to enhance the impact of a clinical education/information resource. This is considered in both the use of creative methods for data collection and in the use of creative or visual methods in the proposed resource. The use of the arts in health and social care, for therapeutic purposes, research, communication, increasing understanding of patient experiences and for enhancing health and well-being has been highlighted by research summarised by the All-Party Parliamentary Group on Arts Health and Well-Being (2017). The use of creative methods within co-design can support greater engagement in the design process, more accessibility to those who find solely verbal involvement difficult and provide a shared sense of understanding between stakeholders (Holliday, Moody and Ward 2017).

The positive impact of adopting creative and visual methods was evident in several areas of the thesis; in the level of participation in the workshops, quality of conversations between participants, in how the participants approached the questions and tasks in the workshops and in how the data was analysed and findings reported. In addition, once participants began to explore how the content they were identifying as important should be conveyed or presented, they turned to methods such as films of patients and clinicians talking about their experiences, patients making films about themselves and filmed role plays as preferred methods.

Participatory visual and creative methods are often adopted when working with marginalised groups in research (Banks 2018; Kara 2015; Mannay 2015; Prosser 2011). Mannay (2010) highlights the potential of visual and creative methods in suspending preconceptions when the researcher has knowledge or experience of the group or phenomena being explored. This was useful to consider in the researcher's role as a clinician working in this field. Methods such as photo elicitation and video diaries have been commonly adopted by researchers exploring marginalisation (Bendell and Sylvestre 2016; Budig et al. 2018; Prosser 2011; Wang and Burris 1997). As this study was aiming to engage a marginalised patient group, including visual and creative ways of collecting data and encouraging participation was important. In addition, frontline staff can also feel disempowered to share ideas and so the inclusion of these methods benefited clinician participants as well.

The researcher's clinical practice draws upon the work of Sean McNiff. In his 2008 book *Trust the Process*, McNiff explores the process of creativity and the need to work with uncertainty in creative work, echoing Simpkins and Schwartzstein's (2016) study which also highlights the need to accept uncertainty in clinical practice. The research process had some parallels with this theory and co-design particularly, relies on not having a fixed end point and allowing the rounds of co-design to inform each other and for participants to define the content and process alongside the researcher (Macdougall 2012; Sanders and Stappers 2008; Sanders and Stappers 2014). The inclusion of visual and creative methods enhanced participants ability to work with the uncertainty of the process and explore areas of practice where they felt underconfident. Being able to draw diagrams or images appeared to help participants explore and emphasise their views in the workshops. In addition, the researcher's professional training as an art psychotherapist helped him to "sit" and feel comfortable with the uncertainty of recruitment, of how the workshops would work, of how participants would interact and how participants would respond to the research topic and tasks.

> *'If we are able to sit with a situation, it will carry us to a new place' (McNiff 2008: 22)*

In the first workshop, participants were asked to think about possible content of a resource and possible format or 'look and feel' issues and ideas. The groups were intentionally multi-agency, multi-disciplinary groups of different people with different roles, as highlighted earlier in the discussion. The use of creative methods for collecting data allowed participants to select pens, papers and other art materials, and jot ideas down whilst discussing their roles, backgrounds and feelings about the subject matter of the session. The workshops were deliberately time-limited to two hours to allow people with health issues, carer responsibilities or clinical pressures to participate. This included the time taken by the researcher to introduce the sessions, people to arrive and settle and for latecomers to arrive. So the groups had to work quickly to get to know each other, allow different people to speak, and to respond to the tasks and prompts set by the researcher. It was noticeable that the room felt active and dynamic. Sunderland (2008) states that by engaging creatively, people are more able to think creatively and this was evident in the workshops. The use of art materials allowed participants to be playful and creative in how they expressed ideas.

Interestingly, and not expected, the use of art materials in the workshops also acted as a leveller between different participants. As highlighted in the review for this thesis

(Chapter 3) one concern about bringing patients and carers into co-design processes is ensuring equity amongst the group (Blackwell et al. 2017; Borgstrom and Barclay 2017; Springham and Robert 2015; Tee and Üzar Özçetin 2016; Terp et al. 2016). This is also an issue between professionals of different levels and backgrounds, when it can be hard to perhaps express feelings about areas where staff feel a lack of confidence in a small group with their line manager. In these workshops, patients and carers and frontline staff attended as well as consultants and senior clinicians. The art materials allowed a different hierarchy to emerge between participants, where those who felt confident using them felt more able to contribute initially. This was evident in one workshop where two student nurses attended and were very confident about using the materials and took the lead in their group, capturing the discussion and feeding their ideas into the conversation in a way which could have been more difficult without the art materials. Less confident members of the groups quickly picked up pens and paper and began to capture the discussion once they realised it was not about being able to draw well.

One of the most significant observations made by the researcher during the co-design process was that it offered participants a meaningful way to engage with areas of practice and personal experience that had been uncomfortable or unknown. Sunderland (2008) explains how creative methods can be used to help people clarify, identify and organise their feelings

> *'seen in the [image], apart from you, objectified, in some sort of form or order, difficult feelings can cease to hold so much power. Their intensity is reduced' (Sunderland 2008).*

Both for patient and carers, who may have had difficult experiences to share, and for clinical staff who were being asked to explore their own lack of confidence, knowledge and skill, a co-design process could be exposing and uncomfortable. The use of creative methods helps to mitigate this and to improve equity between participants. As participants began to focus on creating a resource, they became more engaged in what they found difficult about their clinical practice and how it could be improved through the resource. Patient participants were able to offer lived experience to shape this process and through making, the participants appeared able to tolerate discussions which in the previous study, clinician participants had found challenging and which had produced a more defensive response. McNiff (2008) highlights how things which people find difficult often provoke creative responses

'what disturbs you the most may have the most to offer your creative expression' (McNiff 2008)

The paper prototyping techniques used in the second workshops allowed the participants to think very specifically about how the concepts for the resource would develop into an actual resource. Rather than focusing on broad concepts and content beyond the scope of the research study, the paper prototyping process encouraged participants to focus on how the content they had generated would actually be presented, and how the resource could actually work in practice (Nessler 2016; Snyder 2004). By providing mock 3-D screens made from mounting board, which look like a web-screen, participants were able to think about how actual screen-based content might be conceived and work (see Figure 8, Chapter 6 Co-Design Findings - Workshops).

Sunderland's view that engaging creatively promotes creative thinking (2008) was evident in the prioritisation of the content data. As outlined in Section 4.8 (Sampling and Recruitment) in Chapter 4 (Methodology), the prioritisation of content took place prior to the paper prototyping and rather than ask participants to rate content on a survey or feedback sheet, the groups were given all the content on small cards and asked to work as a group to prioritise what they had identified as possible content. The groups participated in this activity actively and discussed at length the different types of content they had generated. The type of content the groups prioritised was largely narrative type content presented through visual means as opposed to the information-based guidelines and policy content (identified as lower priority). The impact of visual methods for telling patient stories has already been well-established in resources such as HealthTalk (www.healthtalk.org/) and PhotoVoice (www.photovoice.org/). These resources use visual methods to enhance the impact of patient and carer experience and the resource developed from this research will build on these methods and make use of similar techniques to explore issues concerning building confidence and knowledge about working with people with SMI and terminal conditions. In addition to the prioritisation of different types of content, the researcher observed that as participants engaged with the art materials, they became more creative in their suggestions for how content could be included, and began to discuss things like artwork, poetry and photography as well as film.

The use of visual methods not only in data collection, but in the concept of the resource was a strong theme to emerge. As highlighted earlier, being creative allows people to use different parts of the brain to think about ideas and problems (McNiff 2006, McNiff

2008, Sunderland 2008). Visual thinking is a different way of thinking to verbal discussion based-thinking. By using creative methods to talk and discuss and generate ideas, participants were able to view problems and issues from a different perspective, to hear each other's perspectives and generate the concept from the benefits they were experiencing in the room at the time. Talking across discipline, thinking about what the challenging areas of practice are and how they could be addressed, whilst working visually, brought them much closer into contact with the material and the tasks than a traditional focus group would have done. McNiff (2008) states that creativity has its formal aspects, and indeed, these workshops had to be structured and have some boundaries, but that the transformative aspects of creativity rely upon periods of uncertainty and emergence. This was indeed the case in the co-design process and in the wider research study. The iterative process inherent in co-design is important in this regard. The outcome cannot be defined and should not be defined, but neither should the journey to the outcome (Borgstrom and Barclay 2017; Donetto et al. 2014; Sanders and Stappers 2014). Although in health research the research process and methods must be stated in advance to meet ethical requirements, the co-design methodology allows for an iterative process and a creative process to allow ideas to form and emerge.

One of the aims and supporting objectives of the study was related to the development of co-design methodologies and the analysis of co-design data. Whilst, as the literature review highlighted, co-creation and co-design methods have been used for some time now, and their benefits and challenges well-described in the literature (Borgstrom and Barclay 2017; Fox et al. 2018; Palmer et al. 2018), a noticeable gap, highlighted in Section 3.4.2.1 (Inconsistencies of Methodological Approach) in Chapter 3 (Literature Review) lies in the published evidence concerning how visual data generated in co-design is analysed. One of the aims was to contribute to the developing evidence base for the method, but particularly to contribute to the methods for data analysis. The objective was to provide a rich description of data analysis methods as this is what is poorly addressed in the published evidence. Most of the literature tends to focus on describing the process of data collection and the benefits to participants and the end product of adopting the methodological approach (Palmer et al. 2018). Challenges are focused on resources intensiveness, sustainability etc. rather than how to handle the data and artefacts created. This thesis has included a visual description of the data analysis process and visual methods of presenting findings using photographs of original artefacts to illustrate the tabled findings. This will form a useful description for future researchers wanting to explore how to analyse co-design and other creative visual data.

This also forms one of the recommendations for future research outlined in Chapter 8 (Implications, Recommendations and Conclusions).

To conclude, the use of visual and creative methods in the research process and in the developed concept for the resource, offered benefits in many ways but notably in sitting with uncertainty, encouraging creative thinking, creating greater equity between participants, enhancing the role of participants as designers and in reducing stigma. In addition, a contribution has been made to the development of visual analysis methods which is under developed in the published literature.

7.5 Reflexivity and methodological considerations

7.5.1 Reflections on the research design and methodologies

It is possible to view co-creation approaches uncritically, as a panacea to all healthcare problems. Certainly, co-creation approaches, whether described as co-production, co-design or co-creation, are increasingly popular in healthcare research and service improvement. Creative approaches within co-creation are also increasingly popular, with researchers being encouraged to use creative methods to collect data and in the facilitation of co-creation groups. As an art psychotherapist, these approaches are familiar, and the benefits and risks of working creatively are well understood by the researcher. This may not always be the case and further research into the ethical issues of using creative methods and the approaches to data analysis of visual material, have been identified as recommendations for future research, outlined in Chapter 8 (Implications, Recommendations and Conclusions).

As highlighted in Chapter 2 (Contextual Background), previous research concerning the end of life care needs of patients with SMI had failed to involve them as active participants (Jerwood 2016). It would have been possible simply to invite patients and carers to participate in the co-design workshops. However, the stories and experiences of this patient group can be complex and characterised by traumatic past experiences of accessing healthcare, social isolation, poor mental and physical well-being and multiple experiences of stigma and discrimination. Consequently, to invite patients and carers to participate in a workshop-based co-design process, without first having opportunity to share their personal stories and experiences, felt problematic. Their views and experiences would no doubt have been included through their involvement in the workshops. However, the degree to which they may have felt able to participate equally

or share their experiences may have been an issue. Understanding the views and experiences of patients with both SMI and a terminal illness was a key aim of the study because they have not previously been sought. This forms one of the contributions to knowledge of the study.

Including space and time to interview patients and carers, prior to carrying out the co-design workshops, served several purposes within the methodology. Firstly, to focus on understanding individual experiences and circumstances. By inviting participants to spend time individually with the researcher and to participate in an interview of around an hour in length, they were able to share their stories in detail. There was space for the researcher to ask follow-up questions, for participants to take time out when needed and to allow participants to tell their stories in their own way. Patient participants appeared to find this cathartic. In addition to generating rich and valuable data for the researcher to analyse, the process of telling the story allowed participants, both patients and carers, to recount their experiences from their own perspective. It may have been intimidating to go straight into a multi-disciplinary co-design workshop with other patients and professionals, who may or may not be known to the patient or carer. This may have increased the potential for the power imbalances within healthcare, between patient and clinician, to play out. This, inevitably, would have impacted upon what patient and carer participants shared within the sessions. In addition, patient well-being fluctuates and carer availability is variable, often depending on the patient's health. In offering participants a chance to take part in an interview, people who may have struggled to manage in a co-design process were able to take part.

Additionally, recruitment to the patient and carer interviews was potentially going to be a key area of challenge for the research study. The research questions arose from the researcher's observations in clinical practice, many of which centred on the difficulties clinical staff had in talking with patients about their mental ill health and end of life care needs. The research design relied upon clinical staff identifying patients and circulating information about the study to them, as well as other strategies, such as displaying posters, use of social media and newsletters. In reality, recruiting to the interview stage relied upon the researcher attending patient forums, staff meetings and finding opportunities to talk about the research study face to face with potential participants, as well as clinicians identifying participants themselves. Despite a focus on producing accessible written materials, including seeking advice and feedback from patient groups, people responded far more openly to a face to face explanation of the aims of the study

and seemed to have needed space and time to ask questions about which patients would be appropriate. On reflection, this could have been built into the research design more extensively and more time allowed to recruit in this way. This was also true when it came to identifying patient and clinician participants for the workshops. Clinicians and patients seemed to need to hear about the study face to face. When they did, they engaged very well but there were limitations on how much time a lone researcher could spend attending individual meetings and forums. This proved to be a limitation of the research design.

In contrast, the carers who came forward had heard about the study via the publicity materials and identified themselves. As highlighted at the beginning of Chapter 5 (Co-design Findings – Interviews), it was the carers of people who had died, coming forward, who prompted a revision to the research design. They had valuable experiences to share and it was important to capture them in the data collected, as their views were also missing within the published literature.

The research design, described in Chapter 4 (Methodology), specifically Section 4.3 (Research Approach and Design), had considered that patient participants would have people in their care network who would take part. The definition of carer was deliberately broad, not limited to family members. The use of informal care network (ICN) as a definition allowed for anyone who a patient felt was part of their unpaid care support, such as a neighbour or church member, to be included. In reality, only one patient felt they had someone in their ICN who would be suitable for interview. This illustrated the degree of isolation experienced by patient participants, which is also highlighted in the literature review findings (Jerwood 2016) summarised in Section 2.3 (Summary of Previous Research Projects).

Co-design methods are flexible novel and the research design can be adapted to suit the clinical setting or research questions, whilst retaining the rigour of the methodology, as highlighted in Chapter 3 (Literature Review) and earlier in this chapter. This was the case in this study. However, the time commitment for a co-design-based study was an issue which required careful consideration. It is very hard for clinical staff to have time away from clinical settings. The use of multiple cohorts, varied locations and times of sessions, limiting commitment to two workshops and a feedback session only, aimed to mitigate against this risk issue. Nevertheless, for some participants, this time commitment was still prohibitive to taking part. The researcher considered holding workshops on-site, however, the aim was to bring different participants together, to get

the diversity of participation, so holding workshops in different clinical settings would make it easier for one group of staff but more difficult for another. The researcher arranged a range of locations, which were publicised from the start, to allow for clinical staff to plan attendance. It is not easy to see how this issue could be resolved as it is a reflection on the pressures faced by frontline staff and the fact that participating in research is a voluntary activity.

Interestingly, one of the most challenging groups in this study to engage with was community mental health staff. However, those who did engage reported a real avoidance of dealing with death, terminal illness and physical health issues more generally. At most, they felt colleagues would want to know who to refer a patient to, rather than seeing a role for themselves in providing end of life care. Further research should seek to engage with a larger number of community mental health staff, to better understand their views, concerns and experiences and to support them to improve practice.

The patient participants this research aimed to engage with are often very physically and mentally unwell. It was always understood by the researcher that he would have to be flexible and responsive to any patient expressing an interest in the study and to accommodate their needs where at all possible. Patients who came forward were able to take part in in the interview stage, but most were too unwell to commit to participate in the co-design workshops. The need to bring together all stakeholders in the co-design process meant that the location of the workshops was sometimes difficult for patients to travel to. A limitation of the methodology, but also its strength, was the aim to bring together patients, clinicians and researchers in the co-design process. In bringing people together, different participants were able to encounter each other and break down some of the fear and lack of confidence they had, but it also proved difficult to find locations accessible to everyone. Unfortunately, this meant that some patients were unable to participate at the workshop stage, due to poor health. This was mitigated by recruiting peer support workers (patients by experience) into the co-design process. However, in future research, finding a way to overcome this barrier would add value. It is interesting to note that it was participants' physical well-being that was a barrier to taking part in the workshops, rather than their mental well-being. This was an unexpected finding.

It is well-documented that caseload holding and frontline clinical staff are under immense pressure (Dacre 2017; Robertson, Wenzel and Thompson 2017). The recruitment to this study took place in 2017, during a period where the NHS faced significant and

unprecedented pressures on its resources. Although mental health, palliative and end of life care inpatient staff, including medical representatives, were well represented, it was very challenging to engage with clinicians from community mental health teams and community palliative care services. Hospice staff engaged well at a number of different levels and there was some representation from acute inpatient hospitals. There was no representation from primary care staff, despite wide circulation to GP practices. Some of the clinical staff who would have ost benefitted from the resource developed were the most difficult to engage. Community mental health trust staff were very difficult to recruit to the study and were some of the clinicians who were most resistant to accepting that PEOLC is part of their work.

As discussed previously in Chapter 4 (Methodology), the original intention had been to involve members of patient participants informal care networks in the interview process and then, by negotiation, in the co-design workshops. Only one patient participant had a carer who was able to take part. However, a number of carers, who had been bereaved, approached the researcher and wanted to share their experiences of caring for people with mental illness and terminal conditions. It was felt by the researcher and supervisory team that this was valuable data to collect and would add to the study so an amendment was submitted for ethical and governance approval and approved. Therefore, two carers, whose family members (husband and father) had recently died, took part in interviews. Neither carer felt able to take part in the co-design workshops due to work and family commitments. The carer representation in the workshops came from clinical staff, who also had caring responsibilities for a person who met the criteria. The main limitation, regarding carer participation, was in recruitment but also the size of the study.

Within Chapter 4 (Methodology), Section 4.7. (Recruitment and Sampling), presented the approach to participant recruitment. The research participants were predominantly recruited from two main mental health trusts and three hospices. The call for participants was also circulated via social media and members of other organisations responded and participated. However, there are limitations to the number of workshops and interviews which could be accommodated, within the scope and timeframe of the study. This impacted upon the number of organisations who took part as sites and therefore, placed a limit on the variety of clinicians who participated. The researcher committed to visit any patient or carer participant who was unable to travel to one of the research sites in acknowledgement that sometimes people are too unwell to leave home. This also impacted upon the range of patient and carer participants who could take part.

The original study design included a celebration event for all participants at the end of the study. This was going to be held separately from any other dissemination events, with non-participating stakeholders, which would take place later, following the completion of the study. However, once the sites expanded, to cover a wider geographical area, it was not feasible to invite all the participants to one event. Part of the function of a feedback event within co-design, is to allow feedback on data collected, in the same way interview transcripts may be sent to participants to check for accuracy. Partly in relation to the issues of participation raised above, participants found it difficult to commit to attend a further event and seemed to perceive it as not part of the research, more an optional event. On reflection, it would be described differently in the original material, and in fact, calling it Feedback Event may have contributed to this, rather than calling it Workshop 3. Instead, the researcher invited all participants to come to a feedback session and offered three different times, to enable participants to choose a session which suited them. The patient participants did not take part in these events, as each person's health had deteriorated by the time of this part of the research and one patient had died. This part of the co-design process (co-refining) is one that requires further attention with participants that are at end of life.

7.5.2 Reflections on quality issues

Considering the quality of qualitative research is important in ensuring rigour and robustness of qualitative studies (Flick 2018). As outlined in Chapter 4 (Methodology), Tracy's (2010) criteria for assessing quality of the research have been adopted within the study. This section will reflect upon quality issues within the study, prompted by the use of the criteria. A summary of how the study meets each of Tracy's (2010) criteria is included below. Fuller, critical consideration of each criteria is included in the relevant section of the rest of the chapter or other chapters within the thesis and referenced in the table below.

Quality considerations have been addressed throughout the study, from the early stages of research design, particularly in ensuring that patient and carer voices were strong throughout the research study. It was important, as an early career researcher and PhD candidate, to make effective use of the supervisory team, particularly in the development of the protocol, following initial analysis of the data and in creating space to reflect and ensure reflexivity, ensuring the research was high quality, rigorous and credible. The development of the research protocol was key to ensuring the research design was robust. This took a significant amount of time, including consultation with the University

patient research group and service user engagement team at the sponsoring NHS Trust site. The Research and Innovation teams in the participating Trusts were also crucial in ensuring the correct approvals and permissions were in place, and despite the research concerning a vulnerable patient group, the NHS ethical approval was quickly obtained.

For a lone researcher, the supervisory team were therefore vital in the collection and analysis of the co-design data. The development of themes from the interview data involved several rounds of analysis and members of the supervisory team supported this process in the absence of a larger research team. Within the workshops, having a co-facilitator enabled the researcher to focus on facilitating the groups, whilst the co-facilitator made field notes. This also allowed the researcher and co-facilitator to reflect on each group after it finished. The inclusion of a co-facilitator also ensured greater rigour, as a second person, in addition to the researcher, was able to contribute, to the data collection and analysis process.

Reflexivity is a key practice within qualitative research. Throughout the research process the researcher was reflecting on the process of the different stages of the research, using supervision to consider the progress of the research and the researcher's role, particularly within the data collection and analysis process. This research study came about as a result of observations within the researcher's clinical practice. Issues of being an insider researcher are included later in this chapter in the personal reflections (Section 7.6.5). As this was an exploratory study, it was important for the researcher to maintain a curiosity throughout, and continually to reflect through writing and discussion in supervision, and not to make premature conclusions or assumptions. The principles and practices of co-design enhanced this because the data analysis was iterative and was presented back to the participants throughout the process, encouraging thought and reflection throughout.

Tracy (2010) highlights the importance of sincerity in qualitative research. The research journey did not always go as planned, sometimes unexpected things happened, or changes needed to be implemented. Throughout, these unexpected events, although challenging, have been considered as enriching and added to the quality and depth, but also the sincerity, of the research process. Honest reflection of the limitations to the study, how risks were mitigated against, how unexpected findings have been reported and the novel contributions of the study, have been included within the thesis.

Most importantly, the voices of participants, their views, experiences and expertise must shine through into the findings, conclusions and recommendations. Participant quotes

and artefacts have been included throughout, to illustrate how the findings have emerged from the data collected, through the analysis process. The eight criteria in the Quality Framework have been addressed throughout the thesis. The following table (Table 23) provides signposting where specific sections of the thesis address a specific quality criteria and include discussion of other relevant key points.

Table 23 Reflections on the Quality Framework (Tracy 2010)

Criteria for quality (end goal)	**How has this thesis addressed the quality criteria?**
Worthy topic	The topic originates from observations in clinical practice. Scoping research found limited published literature since a review in 2008 (Mental Health Foundation 2008) which highlighted the barriers to care and called for more research to be carried out, particularly involving patients and carers. In addition, a recent focus on both broadening access to palliative and end of life care and on improving the physical health and healthcare of people with SMI at a policy and strategic level, meant that this thesis is both timely and relevant. There have been other studies which focused on the needs of marginalised groups such as, homeless people ((Webb et al. 2017)) and people with learning difficulties (Marie Curie 2019, NHS England 2017) and of marginalised groups more broadly (Stadjuhar, 2019) but there continues to be very limited research published which looks at the PEOLC needs of people with SMI, and particularly, research which attempts to improve care (Donald and Stajduhar 2019).
Rich rigor	The research was carried out within the confines of time and resources of a PhD studentship. This impacted upon the time spent on data collection and recruitment to the study. More time in this phase may have expanded upon the range of participants recruited to the study and the numbers of interviews carried out. Reflections on recruitment and sampling are included in **Section 7.6.1**. The data collection and analysis processes are outlined in **Chapter 4 (Methodology)** and are clear and transparent. The co-facilitator role was critical in the workshop stages and shared reflection after each workshop supported the iterative data analysis process. The use of members of the supervisory team in the analysis process enhanced the rigour of the data analysis and the development of the themes within the findings. Taking part in interviews allowed the participants opportunity to provide rich accounts of their experiences. The thematic analysis of these interviews includes participant quotes which were then used to support the workshop stages.
Sincerity	The study came about from observations in the researcher's clinical practice and a reflection on the role of the partial insider researcher and personal reflections on the research process are included in **Section 7.6.5.** The theoretical underpinnings of the study, methodological approaches, research design and methods are clearly outlined in **Chapter 4** (**Methodology)**. Reflections on the choice of research methods are included later in this chapter in **Section 7.6.1.** The impact of listening to the research interviews and hearing the stories of multiple experiences of poor care, led to an even greater desire to amplify the voices of a very silenced and marginalised group. As custodian of these experiences, the researcher held responsibility for telling these stories, and allowing them to influence and develop the clinical resource. Transparency is important in ensuring sincerity within the research. The methodology chapter provides a transparent account of the methodological process, including changes and amendments made. The Discussion and Limitations include consideration of areas which were unexpected or where improvements could have been made.
Credibility	Rich descriptive interview findings, illustrated by participant quotes, are included in **Chapter 5 (Co-Design Findings – Interviews)** and the co-design process involved a wide range of 'voices' including patients, carers and clinicians, from a range of professional backgrounds and clinical settings. Data analysis was iterative and each round of analysis informed the next round of data collection, allowing for participant checking of emerging data themes.
Resonance	The research aimed to elevate the voice of patients and carers, as well as including clinicians, patients and carers in the development of the resource itself. The interview stage offered rich findings, illustrated with participant quotes. Themes are drawn from these interviews, which illuminate the field in their own right, as well as having been used to inform the workshop stages of the co-design process. The content and format of the resource and its key features are summarised at the end **of Chapter 6 (Co-design Findings – Workshops)**. The process for developing the resource is illustrated and presented in full in **Chapter 6**. Three different cohorts of participants took part in the research to ensure, within the confines of the PhD timescales and resources, that data collected resonated across the cohorts. The co-design process involved presenting the data back to each cohort in each round, allowing for discrepancies of anomalies to be identified.
Significant contribution	The study makes original contributions at a practice, methodological and policy level, which are outlined at the end of **Chapter 7 – (Discussion).** The existing literature was limited, as identified in a previous literature review, and this study makes novel contributions to the published evidence base. At a practice and policy level, the research study has already made tangible contributions – at a local level a Palliative and End of Life Care policy has been developed in the researcher's employing Trust; at a national level the researcher has presented two webinar's which are included in the NHS England and HEE work on marginalisation in PEOLC. Recently an NIHR themed call on PEOLC included people with SMI, as a marginalised group, for the first time.

Ethical	Full ethical approval was granted for the study by the NHS REC, Coventry University and participating organisations (outlined in **Appendix 3 Ethical Approvals**). Reflections on ethical concerns are discussed in **Section 7.6.3** of this chapter. The advantage of going into the research process knowing that the research would be carried out with a potentially vulnerable participant group was that ethical concerns were discussed from the outset. Through reflexivity and reflection, the researcher ended up making amendments to the research design, which involved ethical amendments being applied for from the NHS REC and HRA. Although this created a short delay, it added a depth to the data and further insights into the research topic and the outcomes of the research study overall.
Meaningful coherence	The discussion of findings, conclusions and recommendations for practice, policy and future research, present answers to the aims and research questions of the study. The methods adopted to answer these questions and aims are outlined in **Chapter 4 (Methodology)** and discussed earlier in this chapter and in **Chapter 8 (Implications, Recommendations and Conclusions)**. The discussion considers the findings in light of the existing literature and considers implications for clinical practice and how care can be improved through the development of the resource. The PhD sits in the context of emerging research on the palliative and end of life needs of people with SMI, and other vulnerable groups. One of the aims was to develop the concept of a resource which helps clinicians feel more confident and less fearful in their practice. As it was an exploratory study, there was much to be curious about and much to understand, it was not possible to develop the resource into a full prototype within the confines of the PhD timescales or funding, but rather to understand what it was that clinicians needed, through helping them to consider differently the needs of patients and carers. The end concept has been developed by clinicians, patients and carers in partnership with the researcher.

It is important to reflect throughout the study on issues of quality and consider the particular ways that quality issues are addressed in qualitative research. As a novice researcher, carrying out an exploratory study, this is particularly important. From the design of the study during the data collection and analysis stages, and throughout the writing of the thesis, it has been vital to consider how to ensure the quality of the study. Adopting innovative research methods adds particular challenges, but also a richness to the reflexive process throughout the study stages. The next section explores the particular ethical issues within this study.

7.5.3 Reflections on ethical concerns

As highlighted in Section 4.4 (Ethical Considerations), undertaking research with people with SMI and terminal illnesses was potentially, ethically, problematic. Indeed, much of the early part of the research process centred around developing a protocol which would address all of the ethical concerns relating to this patient group. People with SMI may have fluctuating mental capacity, but more commonly, fluctuating mental well-being and complex relationships with services and professionals which can make recruitment to research studies complicated. It was important that the research activity did not affect any patient participant's usual clinical treatment. This was made clear in the PIS and verbally by the researcher. One participant initially found it difficult to understand that he was participating in a research study, not receiving therapy, but this was resolved by a discussion using the PIS as a framework to help explain what the purpose of the research was and the researcher's role. In addition to fluctuating mental well-being, the patient participants in the study also had fluctuating physical well-being. It was important to be

flexible and allow for interview cancellations, change of venue and other unexpected changes.

In addition, the patient and carer participants, and some of the clinician participants, who were also carers, were potentially easily identifiable by their combination of conditions, or those of the person they care for. Pseudonyms were used to protect participants' identities, and unusual health conditions were referred to in blanket terms to protect patient confidentiality and to ensure participants felt safe in sharing information about themselves in the interviews. It can be hard for participants who are receiving services to be frank about their experiences if they fear being treated negatively as a result. Full transcripts were not made available to anyone other than the researcher and supervisory team, even in anonymised form. Quotes were carefully chosen so as not to reveal a participant's identity. This felt particularly important as participants were being asked to talk about areas of poor practice, or practice which they felt underconfident in, which may have made patient and staff participants feel vulnerable.

The final area of ethical concern was the feeling of equity between participants in the workshops. Interestingly, the use of creative methods acted as a leveller between participants. Some felt more confident with this approach than others and this was not related to status nor to professional background. Clinicians commented on how valuable it was to have patients, carers and other participants such as student nurses participating and the feeling of equity between members in the workshops was noticeable.

7.5.4 Personal Reflections on the impact of the research on the researcher as clinical academic

This study came about from direct observations in my clinical practice in mental health and PEOLC. My identity as both an experienced art psychotherapist and as an emerging researcher run throughout the research journey. The experiences I have had in developing this research study, and in carrying out the underpinning Masters by Clinical Research study have impacted upon both roles.

The clinicians, patients and carers who the research concerns were familiar to me, however, each stage of the research process left me feeling surprised and shocked at the poor levels of care experienced by patients and carers, and the willingness of clinical participants to try to do a better job. This was in contrast to the experiences that the patients and carers have had in services and is something of a reflection on which clinicians, i.e. those motivated to make improvements, chose to take part.

As a clinician the research process gave me a rich understanding of the relationship between research, policy, strategy development and clinical practice. The clinical time I spent in the Trust whilst undertaking doctoral research was made up of clinical supervision of other art psychotherapists and trainees but also in developing a palliative and end of life care strategy for the mental health trust. It was a hugely beneficial part of the doctoral programme to be able to see how research can influence policy and strategy and then clinical practice and ultimately, patient care.

I have approached the research process as someone with a long-held belief in the importance of challenging prejudice and disadvantage. The co-design methodology allowed me to experience working with patients as experts, and as equal stakeholders in a process, and to witness, first-hand, how patients can be viewed differently, as research participants, from how they are often seen in clinical settings. The importance of sharing patient and carer experiences and of patients telling their own stories was highlighted throughout the research process and will impact upon my clinical practice in the future.

In addition, I have gained a richer, deeper understanding of how clinicians learn and how attitudes are changed and shaped, which will impact upon my work as a practice educator in my clinical role. Indeed, I have felt the benefit of undertaking this research very tangibly, as I will be returning to my clinical practice in a senior role, with responsibility for clinical supervision and the training of students.

As a developing clinical academic, I have had the opportunity to build upon the professional portfolio completed as part of my NIHR/HEE Masters by Clinical Research. I have been able to complete over 80 hours of professional development during the PhD programme and develop skills in academic writing, conference presentations and submitting abstracts and articles for publication. These experiences have led me to be asked to present at conferences nationally and internationally, on the subject matter of the PhD research as well as on creative research methodologies. I have been able to influence national and local policy throughout the research process, by developing a Palliative and End of Life Care Strategy for my Trust, delivering two webinars as part of the HEE (North West) Workstream on Marginalisation in PEOLC and the NHS England PEOLC National Workstream, so have had the opportunity to see the impact of the research before the completion of the study. What was most striking was watching the participants in the workshops enact some of what they were trying to develop for the resource, live, in the room. During discussions on the need to provide guidance on how

to have difficult conversations with patients, group members were role modelling and suggesting ways, from their own practice, that other participants could then learn from. Patient participants, although small in number, were able to add a richness to the discussion and the proposed solutions and developments, that clinicians were able to listen to and learn from. The art materials seemed to act as a leveller between different grades of seniority and authority, elevating the more 'junior' group members (students, recently qualified staff) and prompting hesitance in some of the more 'senior' group members (consultants and senior nursing staff).

Furthermore, Art Psychotherapy has been a less research-active profession than other allied health professions and I have been able to contribute, with a small group of other research-active art psychotherapists, to the development of resources and materials to support the development of clinical academic careers. On a personal level, I have developed resilience and an understanding of my own tenacity and determination, which will also impact on my work as a clinician, practice educator and a researcher.

7.5.5 Personal Reflections on being a 'Partial Insider Researcher'

As described previously in Chapter 4 (Methodology), I was employed in two of the participating organisations so was known to some clinician and patient participants. However, due to the size of the mental health trust, and not being employed by the other participating organisations, I was not known to *all* participants. This is described for the purposes of this section as being a 'partial insider researcher'. It is important to reflect on what this means in terms of the potential influences on data collection and this is further discussed within this section. There are contradictory beliefs about whether being an insider researcher is an advantage or disadvantage in the research process. Most importantly it is important to acknowledge the potential impact on the research process, both positive and negative.

On this point, Brannick and Coghlan (2007) argue that there is always an inherent bias in any research and being an insider is not a barrier to undertaking research, rather the knowledge and understanding a researcher holds when an insider, enhances the collection and analysis of data, as long as the researcher remains reflexive and reflective during the process. Certainly, in this study, my knowledge of the clinical setting, experience of working with the patient group concerned and understanding of the training and clinical practice of the clinicians was an advantage. This was particularly so in the early stages, developing the research protocol and obtaining ethical approval. The NHS

Ethics committee were reassured by my professional background when granting ethical approval for the study. Secondly, in gaining access to organisations, circulating details of the study and recruiting participants, the benefit of holding 'insider' status was helpful. There was a definite advantage in having an understanding of both the clinical settings, being able to understand and use the clinical language and have insight into the clinical environment.

Furthermore, Hewitt-Taylor (2002) stated that when time is pressured, being an insider researcher can aid timely access to organisations and potential research participants. In this case, examples such as, of gaining access to room bookings, circulation of recruitment details, obtaining clinical research network support for the study and engaging with other organisations, this was the case. However, recruitment to the study was higher in the organisations where I was not an employee. These organisations seemed keen to make a positive impression and recruit a wide range of participants. Upon reflection, what was important, was that I had knowledge of the field, and so working for similar organisations but in another area was an ideal situation.

If patient participants who were known to me clinically had come forward for recruitment, this may have presented an ethical dilemma. However, none of the participating patients or carers had been previous therapy clients or were likely to be referred for therapy during the period of the research, as I was seconded out of the Trust and the hospice while undertaking the study. Therefore, this particular ethical issue did not arise. Some potential participants had heard about the research, through attending working groups and drop-in sessions about strategy development that I had been involved in, so it was important for me to use the PIS and consent forms (see Appendix 2) to highlight the difference between consultation and research participation.

Some of the potential negative impacts of being an insider researcher relate to impartiality within the recruitment process (targeting 'known' patients and staff, leading to bias). Potential negative impacts include; the perception of what the motivation behind the research might be amongst potential participants (relating to their perception of the researcher's role within the organisation), fear of confidentiality and anonymity being compromised and the possibility of participants wanting to please the researcher. To mitigate against these impacts, as discussed earlier in Chapter 4 (Methodology), I provided clear written information about confidentiality (see Appendix 2 Research Protocol) and reiterated this at the start of each interview or workshop. I also explained how the data collected would be used, anonymised and disseminated, including how

audio recordings and artefacts created would be stored and disposed of. In the interviews, I introduced myself and explained my role as a doctoral researcher from the University who is also a clinician in both palliative and mental health care.

On reflection, the benefit of being a partial insider researcher had more positive than negative impact. The benefit was felt most in the development of the study, the research design and ethical approval process.

7.5.6 Limitations of the Study

This study had several limitations. Firstly, the recruitment to the study. The clinical participants were busy with clinical commitments and it was often difficult, particularly for frontline staff, to leave the clinical setting to attend research study activity. In addition, it was difficult to recruit community mental health team staff because they don't necessarily understand their role in the delivery of PEOLC, which is, in part, what the study was aiming to address. The research design and ethical approvals relied on clinical staff to identify patient participants, and for patient participants to identify carer participants. On reflection, and if time had permitted, it would have been advantageous to consider additional ways of directly recruiting patient participants into the study from clinical settings. Once carers came forward independently, the research design was amended and an ethical approval for the amendment obtained so this mitigated against that particular limitation. Aiming to bring mixed groups of participants together meant that workshops had to be held in locations which were inconvenient for some people. The alternative would have been to run the workshops by discipline i.e. run a mental health workshop onsite in the Trust, and a hospice workshop on-site at the hospice. However, this would have lost the multi-disciplinary aspect of the workshops which was so important in the development of the resource content and concept.

Taking the co-design process to a full product development fell outside the scope of this thesis and research study. The participants were aware that the outcome of this part of the research study would be the concept of a resource. In co-design the outcome is often a modified or new product or service improvement. This may have impacted upon participants' investment in the process.

Secondly, the timeframes and limitations of being a lone doctoral researcher meant that boundaries had to be placed upon the recruitment time periods, geographical coverage of the study and the numbers of interviews and workshops which could be carried out. Future, post-doctoral research will benefit from being able to involve a designer, wider

geographical coverage and in being able to develop the concept into a pilot resource which can be tested in clinical settings.

The third limitation relates to using a novel methodological approach. There was limited literature regarding the structure and analysis methods used, however this is also a key contribution of the study; to develop the methodological evidence base. The aim of the study was to develop the concept and content of a resource, to inform further development into a full-prototype for piloting in clinical settings. The iterative process used within co-design can mean it always feels possible to add further rounds of workshops, to keep refining the product to be developed, without coming to an end point. Some boundaries were placed upon this, linked to the limitation about timeframes and being a lone researcher. There is some question, therefore, surrounding when co-design is complete.

The fourth limitation relates to the nature of qualitative research, where the researcher is an agent within the research process. There is possibility for bias to be introduced by the researcher, and the research process influenced by the researcher's beliefs and attitudes. The processes to mitigate against this have been explored in Chapter 4 (Methodology). The role of the researcher as, 'partial insider researcher' is critically reflected upon in Section 7.2.1 earlier in this chapter.

7.6 Contributions of the study

This research study makes original practice, methodological and policy contributions to scholarship in the fields of palliative and end of life care, mental health and participatory research. The nature of each contribution is outlined in this section.

7.6.1 Practice contributions

It is believed that this is the first research study that has explored the views and experiences of people with SMI and a terminal condition, about their palliative and end of life care needs and expectations. The views and experiences of this group of patients and carers were not previously known, as highlighted in Chapter 2 (Contextual Background). Previous studies included the views of patients with SMI, but not a terminal condition, or used retrospective reviews of notes or case studies. In addition, the views and experiences of carers were also included. The study presents a thematic analysis of a series of interviews and presents key themes, which were used to inform the research process but can also be used to inform future research studies, the development of strategy and policy at local and national level and the development of clinical services, which support people with SMI, who have terminal illnesses. There are transferable findings which could also inform palliative and end of life care practice for other marginalised groups.

It is believed that this is also the first study emerging from the UK which aims to develop an improvement innovation to care, for people with SMI, rather than to explore the barriers and problems to providing good PEOLC. The development of the concept and content of a co-designed clinical resource, concerning patients with SMI at the end of their lives, is the second original contribution

The previous, underpinning research, by the researcher highlighted the lack of confidence in clinical staff in both PEOLC and mental health settings, in working with people with SMI and terminal conditions. This was echoed by acute and primary care staff who participated in the study. This second contribution lies in the development of the concept and content of a web-based resource to improve care. Previous research describes the barriers to care and has not progressed innovations to improve care. This research offers the concept and content of such an innovative resource, which has been co-designed by the stakeholder participants and potential end users.

From the findings of this study, some understanding is now known, of the type and range of content required by clinicians, to build confidence, challenge negative attitudes and improve clinical practice, regarding people with SMI and their palliative and end of life care needs. What is also now known is that patients and carers might benefit from access to a similar resource in future, to enable them to hold clinical services to account, by being more informed about the range and type of services available.

7.6.2 Methodological contributions

The main methodological contributions of this study arose firstly, from the use of creative co-design methodologies with this participant group and secondly, a contribution to the development of the methodology, in terms of how visual co-design data can be collected and analysed. It is believed that this is the first time that co-design methods have been used with a mixed group of clinical, patient and carer participants from the mental health and PEOLC settings. The research found that people with SMI and terminal conditions can, and want to, participate in research, and in conversations and planning of their PEOLC needs. This finding arguably challenges existing understanding that this patient group is vulnerable and unable to participate in research studies.

The literature review (reported in Chapter 3) for this study explored the use of co-creation methodologies in both PEOLC and mental health services. The review highlighted the potential for using co-creation methods in both clinical settings, and the benefits of doing so, but also the need for structured approaches for using non-EBCD co-design methods, particularly the collection and analysis of visual data. This study presents a rich description of the data collection and analysis processes which can be adopted by other research teams in the future.

7.6.3 Policy contributions

The findings from this study could be used to inform policy at local, regional and national level, both in terms of how services are commissioned and how best practice is shared. The findings in this study can support the inclusion of issues surrounding the end of life, long-term and terminal conditions which people with SMI experience and in achieving parity between mental and physical health services in national policy and guidance. To date, the policy surrounding the improvement of physical health and access to physical health services has excluded palliative and end of life care issues.

The findings also support a re-consideration of the negative, unintended impact of the 'recovery' agenda in mental health services. People with incurable conditions are still perceived to be outside the focus of recovery services and indeed, sometimes still perceived to require no treatment or support from mental health services following diagnosis of a terminal condition.

The findings highlight the problems with an ongoing separation of mental and physical health services, with wider impact than just for patients with SMI and terminal illness. Clinical training, particularly in medicine and nursing, but also in the allied health professions, to some degree, promotes specialisms and separates mental health from physical health. Whilst specialisms are necessary, people with mental ill health also need to access other health specialisms and be treated by clinical staff, with the appropriate training in mental health, to meet their needs with confidence and respect. The recommendations from this study include better inclusion of working with mental illness in general health training and better coverage of working with patients at the end of their lives, in mental health training. This does not just apply in nursing, but across all healthcare professions.

The findings from this study also support initiatives which seek to increase access to palliative and end of life care. These findings demonstrate that more still needs to be done to increase access to PEOLC for people with SMI. The findings can be used to ensure that initiatives at national and local level, which seek to engage marginalised communities in PEOLC, address the specific needs of people with severe mental illness.

7.7 Chapter Summary

This chapter has critically discussed the findings of the study and how they answer the research questions. Overall, patient participants and carers had strong views about how they wanted to be treated and what their expectations of care were. Sadly, their expectations were rarely met and patients and carers reported repeated, negative treatment in many different areas of healthcare in relation to their treatment as people with both SMI and a terminal illness. Echoing the findings of a previous study of clinician views, the lack of confidence, and underlying fears, of clinical staff was a key barrier to providing good PEOLC.

The co-design process offered a small group of patients, carers and clinicians to work together with the researcher to develop the content, format and concept of the resource. This process was rich, dynamic and challenging. Participants were highly motivated to

think creatively about how attitudes to people with SMI and terminal conditions could be improved. Different participants from different backgrounds, some bringing multiple identities (e.g. as both patient and staff member, or staff member and carer) shared their stories, expertise, fears and creativity in the development of the resource concept. Participants were motivated to make experiences of care better for this patient group, and their carers and committed their time and energy into supporting the study.

The study findings form part of a small but developing field of research in this area. Patients, carers and clinicians needs were at the centre of the study. The importance of improving the experiences of people with severe mental illnesses as they reach the end of their lives has been highlighted and some of the ways in which this can be achieved have been explored and developed. The next chapter will present the implications and recommendations for clinical practice and conclusions to the study.

Chapter 8 Implications, Recommendations and Conclusions

This chapter presents the implications of the study for practice, research and policy with linked recommendations.

8.1 Key Implications and Recommendations

Key implications have been discussed in the previous chapter. Implications and recommendations are set out in Table 24 in three main domains; practice, research and policy.

Table 24 Implications and Recommendations

	Implication	Recommendation
Practice **a) Patients and Carers**	1) Patients with SMI and terminal illnesses want to be, and are capable of, being involved in their care and are often best placed to provide information to clinical staff about their health conditions and care needs.	1) Patients with SMI and terminal conditions should be invited to be involved in all aspects of their care. Support should be provided to achieve this where necessary.
	2) Whilst many people with SMI do not have close family relationships or an informal care network, those who do, have close carers who are an important source of support and expertise.	2a) Carers should be viewed as key members of the care team around the person with SMI. 2b) Carers are sources of expertise and provide crucial care, but also require support and respect from professional clinical staff.
	3) Providing appropriate, high level palliative and end of life care to people with SMI requires flexibility of approach.	3) Flexibility of approach should be encouraged and recognised within the context of individual care planning, rather than seen as bending or breaking the rules.
	4) Patients with SMI benefit from early referral to PEOLC, as they may have more limited support at home, and more challenging relationships with the health care teams, providing specialist condition-related care,	4) Referrals should be made to appropriate PEOLC by the GP, specialist care team or mental health care co-ordinator as early on possible following a terminal or life-shortening diagnosis.

b) Clinical Staff	primary care and sometimes their mental health teams. 5) Patients with SMI, who may experience fluctuating mental health and fluctuating mental capacity, benefit from early engagement in Advance Care Planning. 6) Patients with SMI face stigma and prejudice when accessing healthcare. Previous negative experiences impact upon their views about engaging with new services. 7) Lack of confidence, stigma and fear about mental illness are still prevalent amongst clinical staff in all areas of healthcare and this impacts upon care quality and accessibility. Clinical staff are keen to learn and to improve their own practice but lack the resources necessary to do so. 8) Training courses exist and have a place in developing skills, such as communication, understanding of mental illness and of issues surrounding end of life care, death and dying, but clinicians have extremely limited time and funding to access these courses or they are only available to people of a certain level of seniority.	5) Patients with SMI should be supported to consider and undertake the different elements of ACP, involving family members and *all* clinical staff involved in the patients care – specialist care, mental health care, primary care and PEOLC. 6) Clinical staff require access to information, knowledge and training, which addresses negative views of patients with SMI and working with dying patients. 7) The concept of the web-based resource, presented in this research, should be developed into a full resource, which can be piloted regionally or nationally. 8) The web-based resource should build upon the co-designed concept which uses visual and creative methods to support the development and delivery of content. Patient, carer and clinician stories should be a key component of the resource.
Research **a) Research area**	9) The lack of appropriate resources available to clinical staff, patients and carers is contributing to poor experiences of, and limited access to, palliative and end of life care for people with SMI.	9a) The concept of the resource should be developed into a full resource and piloted widely in clinical settings. 9b) The key features of the resource should include: i) Experiential, Information and Learning Content (section 6.3)

		ii) The resource features and content are presented in **Chapter 6**. In summary, the resource should be: • interactive • narrative-based • challenge attitudes not just provide information • a comprehensive resource for SMI and PEOLC clinicians and others involved in the care of the patient group • include myth-busting, over-arching messages, difficult conversations, communication skills and an overview of the mental health and PEOLC systems • the hosting, look and feel of the resource are important
	10) Clinical staff find it difficult to obtain funding and time to attend training courses or access journal articles and this limits their ability to develop skills and knowledge.	10) The dissemination strategy for the research findings should consider alternative ways to share the findings with frontline clinical staff, including webinars, briefings, short film clips, articles in newsletters, on Twitter and in widely read publications (Community Care, Guardian Online, Nursing Times etc.) which may not be peer-reviewed. Links to the resource and peer-reviewed journals can be added to these forms of dissemination.
b) Research methodology	11) People with SMI and terminal illnesses want to be, and are capable of, being involved in participatory research.	11) Co-design methods are useful when working with marginalised groups and can be used effectively with patients with SMI and terminal illnesses, as well as with clinical staff from both settings.
	12) Co-design methodologies are still emerging and developing and there is a lack of guidance for implementing approaches, other than EBCD, which means that there is an over reliance on one approach.	12) There is a need for more methodology-focused research to be published, which adopts creative co-creation methodologies, including co-design.
	13) There is a lack of published research which concerns the analysis of visual data, which can make analysis approaches inconsistent.	13) There is a need for more research which describes the data analysis of visual research data to be published.

8.2 Final Conclusions

This research study aimed to better understand the views, experiences and needs of patients, and their carers, *and* to develop the concept and content of a resource to improve care, through building the confidence of clinical staff. A key under-pinning principle was to move beyond describing barriers and difficulties and to attempt to develop an improvement intervention or innovation, to improve how people with SMI are supported and looked after at the end of their lives. Drawing from the literature and using the methods as discussed, these aims were achieved,

It is also believed this is the first study which has sought to understand the views and expectations of patients and carers, living with SMI and a terminal illness, about their palliative and end of life care needs, experiences of receiving care, the barriers they experience to accessing care and their views on the skills and knowledge that clinical staff may need to provide better care. Previous studies had been either retrospective studies of clinical notes, retrospective case studies or had not involved patients with both SMI and terminal conditions. This research provides an insight into the barriers to PEOLC and how care could be improved, from a patient and carer perspective, to inform clinical practice, future research and policy development.

Furthermore, this study identified that, despite stigma and prejudice towards people with SMI, fears about their ability to engage in decisions about their care and assumptions about fluctuating mental capacity, people with SMI are able to engage in discussions and decisions about their end of life care. In fact, this is something that they actively want. The study found that rather than being frightening or distressing, being involved alleviated those fears. What patients and carers found more distressing was being ignored, excluded from decision making and abandoned by services. These findings provide new knowledge regarding patient needs and expectations. Patients with SMI are able, and willing, to engage in advance care planning and other care decisions. Sometimes they have limited care networks, but those carers who are involved are often sources of support and expertise and should be seen as key members of the care team around the patient. Additionally, clinical staff often hold the answers to clinical challenges and should be included in service re-design and innovation.

What is also novel is that the research questions in this thesis were developed following observations in clinical practice and a preceding study, which found that clinicians in mental health, palliative and end of life care, acute and primary care,

reported fears, lack of confidence and uncertainty about how to work with people with severe mental illness and terminal conditions. These factors were found to be a significant barrier to providing good palliative and end of life care. The current research has led to greater understanding of their views and the experiences of clinical staff, understanding their perceptions of the barriers to care and how it could be improved, to enable clinical staff to better meet care needs. Building the confidence and knowledge of clinical staff who care for people with SMI and terminal conditions is crucial to the improvement of care and this research will impact upon clinical practice and improve the care experiences of a vulnerable, marginalised patient group.

In addition, patients with SMI, and their carers', views and experiences had not been included in previous research and little was known about their views and experiences of palliative and end of life care. It is known that involving patients, carers and clinical staff in innovations to improve care leads to better quality outcomes. In this study, creative co-design offered opportunities to involve those who will use and benefit from innovations to care. Creative methods have the ability to change ideas, think about problems and solutions differently, affect attitudes and challenge prejudices. The research applied an innovative, creative co-design methodology to developing the concept for a resource, which will address the lack of confidence and underlying attitudes of clinical staff and build awareness and knowledge of clinicians, patients and carers, about providing better PEOLC for people with SMI, as they approach the end of their lives.

The participants in the co-design process concluded that although the resource should include common content, such as guidance, policies and links to related websites and organisations, what they valued was more experiential and learning content, which uses patient, carer and clinician stories sharing of best practice, 'how to' examples and which use film, to allow personal stories and experiences to be shared. Visual and creative methods for presenting the content were important in challenging attitudes to mental illness and death and dying. Additionally, the co-design methodology allowed the voices of patients, carers and clinical staff to be heard, their expertise to be shared, and for the content and format of a resource, which will meet the needs of its users, to be developed. This research can be used to develop a working prototype of the resource which can be piloted in clinical settings.

This research will be of interest to frontline clinical staff in palliative and end of life care and mental health services, but also to acute and primary care staff who also encounter patients with SMI and terminal illnesses. Many of the recommendations are also

applicable to anyone requiring end of life care, and in fact, it is often in improving care for a marginalised group, that care is improved for everyone. The patient and carer interview findings have great relevance across healthcare settings. Post-doctoral research aims to focus on the development of the resource concept into a functioning web-resource and full pilot in clinical settings. The workshop findings and concept of the resource will be useful to these clinical staff, but also to commissioners of education for clinical staff, policy makers and those responsible for the development of improvement strategies, regarding improving access to PEOLC and improving physical healthcare approaches for people with SMI.

People with SMI experience disadvantage and poor treatment in all areas of healthcare. Prejudice and stigma towards mental illness is widespread, and patients with SMI face poor outcomes and discrimination in many areas of life. Receiving a diagnosis of a terminal condition is traumatic and devastating for anybody, but for somebody who has lived with the fear and bewilderment of a severe mental illness, it can be even more distressing. High quality palliative and end of life care can provide patients with support, information, kindness and compassion, at the most vulnerable point in their lives.

Ultimately, this research has the potential to benefit patients with long histories of mental and physical ill health, who are diagnosed with terminal conditions, and those who care for them. People with SMI are undoubtedly vulnerable and experience multiple disadvantages, stigma and prejudice, but they are also resilient, tenacious people who want to, and have the right to be, involved in their care. The findings of this research will help clinical staff to improve the way this group of patients are cared for right until the end of their lives. Moreover, everyone deserves to be supported and guided through the end of their lives, just as people are supported at the beginning of their lives. This is voiced in one final comment by a participant as;

I just needed them to lean in. When I most needed them to lean in, they stepped back' John

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Appendices

Appendix 1 Journal Paper

[removed due to copyright restrictions]

Jed Jerwood, Diane Phimister, Gillian Ward, Nikki Holliday, Jane Coad (2018) *Barriers to palliative care for people with severe mental illness: exploring the views of clinical staff* European Journal of Palliative Care Volume 25 Issue 1 Pages 20-25

Appendix 2 Research Protocol

The research protocol below includes Participant Information Sheets, Consent Forms, Letters of Approval and was the version submitted to the HRA and NHS REC for ethical and governance approval. There is some duplication with the Appendices in the main study because this is the version which was submitted for approval and it includes some early copies of approval letters and insurance documents to the main study Appendices. For ease of recognition the full protocol, appendices and reference list are presented in grey.

Research Protocol v. 3 19/11/2017

Improving End of Life Care for Adults with Severe Mental Illness: Understanding the views of patients, and their informal care networks, through co-design to improve approaches to clinical practice

Research Area

Improving End of Life Care for People with Severe Mental Illnesses and Life-Limiting Conditions

Research Questions

What are the views and experiences of patients (and members of their informal care networks) with severe mental illness, of care and treatment in end of life care services?

How does co-design support the creation of a clinical educational/information resource?

How can the use of visual methods enhance the impact of a clinical education/information resource?

Aim

The aim of this study is to:

> Gain an understanding of the views of patients with severe mental illness, and members of their informal care network, on their palliative and end of life care needs and their experience of accessing and receiving care and to apply this experience to the development of a co-designed educational/information resource for clinical staff.

Objectives

- To explore the views and experiences of patients with severe mental illness and life-limiting conditions on:
  - their end of life care needs (emotional, physical, social and psychological)
  - the barriers to accessing timely and appropriate palliative and end of life care

    - what skills and knowledge clinical staff may need when supporting access to, and delivering end of life care, to people with severe mental illness and how care can be improved
- To explore the views and experiences of carers on the end of life and palliative care needs of patients with severe mental illness, barriers to accessing timely and appropriate care, and the knowledge and skills clinical staff need and how care could be improved
- To co-design the concept and initial content of an educational resource to improve clinical practice with small groups of patients, informal care network members and clinical staff
- To explore the use of visual methods that may enhance the impact of the resource

Investigators

Jed Jerwood – PhD Centre for Innovative Research Across the Life-course (CIRAL)

Diane Phimister - First Supervisor

Nikki Holliday - Second Supervisor

Dr Gillian Ward - Advisor

Professor Jane Coad - Director of Studies

Background

The researcher is an HCPC Registered Art Psychotherapist working in both adult mental health and end of life care. The study question arose from clinical observations and curiosity about the apparent under representation of people with long term mental health conditions receiving end of life care. The methodological approach is informed by the researcher's professional training which places the making of, and communication through, visual imagery and objects at the centre of clinical practice.

There has been a focus on improving end of life care in the UK since the publication of the End of Life Care Strategy in 2008. Community initiatives such as Dying Matters week, BRUM YODO ('You Only Die Once' - a Birmingham-based collective who run events to promote conversations about death and dying), policy initiatives developed by the National Council for Palliative Care, NHS England and the National Palliative and End of Life Care Partnership have raised the importance and profile of end of life care consistently at a policy, strategy and community level.

However, the needs of people with mental illness have not been represented or included in these initiatives. People with long term mental illness die on average ten to twenty years earlier than the general population and experience higher rates of many life-limiting conditions (Chesney et al., 2014). Yet, little is known about their end of life care needs, and little has been done to try to improve end of life care for this patient group.

A systematized literature review (Jerwood, 2016) revealed a limited pool of published research concerning the end of life care needs of people with severe mental illness. What literature existed originated from outside the UK and did not concern current clinical practice. The literature identified the need for further research to be carried out

and comprised some empirical research studies, but mainly included discussion pieces and highlighted the problems of providing care to the patient group – there were very few studies which trialled or piloted new approaches to care.

The findings of the literature informed a study (Jerwood, 2016) which explored the views and experiences of clinical staff on the end of life care needs of people with severe mental illness, barriers to providing good care and views on how care could be improved. The findings of this study complemented those in the literature review calling for further research into the end of life care needs of people with mental illness and highlighting the absence of the voice of patients and their carers in the published research. The confidence and knowledge of clinical staff to work with both mental health and end of life needs was a key finding in the study. Clinical staff described their own lack of knowledge and skill in working outside their own professional discipline – mental health clinicians felt under skilled in working with patients at the end of life and end of life care clinicians expressed the same issue with regard to supporting the mental health needs of patients with severe mental illness at the end of life.

Both the literature review and clinician research have informed the design of this study. The study design incorporates both patient and carer interviews and the co-design of a clinical information/education resource which aims to improve the confidence and knowledge of clinical staff, and therefore approaches to clinical practice.

The methodological approach draws on participatory research and co-creation principles, acknowledging the imbalance of power in traditional research approaches (Green and Thorogood, 2014). The patient group have been marginalised and excluded from service development, published research and in their experiences of accessing care (Shalev, 2017; Mental Health Foundation, 2008; Jerwood, 2016) therefore it is important to ensure the research philosophy and approach acknowledge and address this imbalance of power.

Definitions

There are multiple definitions for both end of life care and for mental illness. For the purposes of this study the following definitions have been adopted.

End of life care is care that:

'Helps all those with advanced, progressive, incurable illness to live as well as possible until they die. It enables the supportive and palliative care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support.'

End of Life Care Strategy 2008

Severe Mental Illness:

There are many different definitions of, and ways of categorising, mental illness. This research concerns people with long term mental health conditions, being treated within the mental health system. Diagnoses are usually categorised using World Health Organisation's International Classification of Mental and Behavioural Disorders Tenth Revision (ICD-10) and may include schizophrenia or psychosis, personality disorder, depression and anxiety and bi polar disorders.

Informal Care Networks:

Members of the patient's informal care network may be family members, friends, neighbours, work colleagues or members of a religious organisation or any significant people close to the patient and involved in their care and support. It offers a more inclusive definition than carer or family member and acknowledges that support and care networks are complex and varied.

Patient and Public Involvement in Study Design

The study arose from discussions and observations in clinical practice and some patients and clinical staff were consulted about the research topic informally in the clinical setting.

The research design plan and protocol will be presented to the Coventry University Research Support Volunteer Programme (RSVP) Patient panel and feedback incorporated into the final protocol and research design.

Birmingham and Solihull Mental Health Foundation Trust's (BSMHFT) User Voice group have been approached and invited to be involved in the form of an advisory group. The Palliative Care Lead's at the Clinical Research Network (CRN) West Midlands and Health Education West Midlands (HEWM) will be approached with a view to presenting the research to patient involvement groups. Local voluntary sector organisations (e.g. ReThink, MIND) working with people with mental illness will also be approached with a view to presenting the research to their patient involvement groups. The feedback and discussions from these groups will be incorporated into inform the on-going design of interviews and co-design groups.

In recruiting staff and patients to co-design groups, patient involvement in the research process will be central.

Literature Review Design

A literature review has already been undertaken exploring the factors affecting the provision of end of life care to people with long term mental health difficulties (Jerwood, 2016). The findings of this review will form part of the background and context to this study.

However, there are two further areas which require review of the literature to inform the design of the research study. As very little research has been carried out in the specific area of clinical practice, this review will look at how similar methods have been used in related fields.

There are two elements to the literature review.

1. How have co-creation methods been used to improve clinical practice in a) mental health services and b) palliative and end of life care services?

The findings of these two searches will give a basis for the rationale of the study. Health, psychology, education and design databases will be systematically searched. Studies with be critically appraised for quality using the Critical Appraisal Skills Programme (CASP) Qualitative Checklist (http://www.casp-uk.net/casp-tools-

checklists) and a thematic analysis (Braun and Clarke, 2006) of the content carried out.

A full literature search strategy is detailed in Appendix 1. Ethical approval for the literature review has been granted by Coventry University Ethics (P47485).

Methodology

Research Paradigm

This study will approach the research questions from a participatory perspective (Reason, 1994; Heron and Reason, 1997). Heron and Reason (1997) place collaborative inquiry at the centre of the participatory research paradigm 'in which all involved engage together in democratic dialogue as co-researchers and co-subjects'.

The beliefs and experiences of the researcher will inform the approach to the research design, placing importance on amplifying the voice of the participant in the research process. The patient group the study concerns are often disempowered and have been under-represented in previous research studies and within the development of strategy, policy and practice (Mental Health Foundation, 2008; Shalev et al., 2017). The clinical staff participants are also often the subjects of research studies or the recipients of service re-designs or organisational change rather than being equal participants in these processes. There are similarities between the experiences of clinical staff and patients in terms of lack of equality within the research process and the research approach underpinning this study aims to address this.

Research Approach

A qualitative approach will be used to explore participant's views and experiences of the research question and address the stated aims and objectives. A qualitative approach is useful where little is known about a topic, or where views and experiences of participants are being sought, or where different perspectives may be held by participants (Bricki and Green; 2015). The research questions include exploring and understanding the perspectives of patients. Qualitative methods will allow the patient experience to be understood and explored.

Participatory research has two objectives – to generate knowledge and action directly useful to a group of people, and to empower those people through constructing and using that knowledge (Heron and Reason, 1997). The design of this study aims to adopt both objectives with a view to improving care through amplifying the patient voice and empowering participants to develop solutions.

Study Design

Participatory Methods

A participatory approach challenges the traditional approach which involves carrying out research about or on participants, and instead encourages researchers to carry out research with participants (Bergold and Thomas, 2012).

Participatory methods will be adopted in each stage of the study. The first stage involves a series of semi-structured interviews with patient participants and members

of their informal care network. Patients will decide who they would like to invite to participate in interviews and will have choices about being interviewed alone, with carers or in small groups with another patient.

The research design described below has allowed flexibility in sample size, structure and format of interviews in an attempt to increase the participatory element in this stage of the study. An inductive approach will be taken, allowing themes to emerge through the patient interviews. It would be possible to take a deductive approach and interview patients and carers using the themes which arose from the literature review or clinician study already undertaken, however, an inductive approach allows the themes which are of concern to the patient to be identified. This is important when working with a disempowered group, and within a traditionally 'top-down' healthcare system.

Co-Design

Co-design methods have been chosen for the second stage of the research to ensure that the process of developing a resource which aims to improve care involves those who will use and benefit from the resource. Participants in the second stage of the study includes both patients (and carers) and professional clinical staff. All 'types' of participant are potential end users of the resource and using a co-design approach allows for stakeholders to become equal partners in the process.

Co-design is defined by MacDougall (2012) as 'an attempt to define a problem and then define a solution'. Sanders and Stappers (2008) define co-design as a specific instance of co-creation. Co-creation is described as 'any act of collective creativity, i.e. creativity that is shared by more than two people'. Co-creation and co-design are becoming more common beyond their design origins, within healthcare settings, with designers working in partnership with clinicians and patients to solve healthcare problems and develop solutions in collaboration (Sanders and Stappers, 2014; Boyd et al., 2012).

Co-design methods draw on participatory methodology by bringing together groups of participants to work together on designing a solution to a problem. In healthcare settings this could involve patients, families, carers, clinical staff and other health or social care professionals. Depending on the nature of the question or problem, different groups of stakeholders will be invited to participate. Methods of data collection may include focus groups, workshops, photography projects, blogs, diaries and mapping processes (Bergold and Thomas, 2012). Creative and visual methods are used to broaden the range of ways participants can participate – encouraging people to tell their stories and articulate their experiences (Sanders and Stappers, 2014). Some groups or individuals may find verbal communication challenging, organisational hierarchies may impact on participants' willingness to contribute to traditional verbal discussions or meetings. Creative methods allow participants to use imagery and symbols to convey knowledge, rather than just verbal discussion or written communication.

Asking participants what they want can lead to a limited discussion based upon what they believe is possible, or currently available. Using creative methods within a co-design process encourages and enables participants to visualize, imagine and

convey ideas and concepts, leading to shared language and understanding (Hagen, 2011).

Methods

This study has two stages – interviews and workshops

1. a) Between 4-6 semi-structured interviews with patients and up to two members of their informal care networks, where appropriate, to explore their views on their palliative and end of life care needs, their experience of accessing and receiving care and treatment, barriers to accessing treatment and views on how clinical staff could improve care. Interviews can be carried out individually, or in as part of the informal care network. This will be decided by the patient in conjunction with the researcher.

   b) Between 4-6 carer interviews, where the patient has died or is too unwell to participate, but the carer wishes to share views on the palliative and end of life care needs of the person they have cared for, their experience of accessing and receiving care and treatment for the person they cared for, their needs as carers, barriers to accessing services and their views on how clinical staff could improve care.
   To ensure participation in interviews is as inclusive as possible, flexible combinations of individual or small group interviews can be carried out. For example, Fig. 1 shows the patient participant could opt to be interviewed with two carers, or each person could be interviewed separately. It may be that some participants prefer to be interviewed together, and subject to both participants meeting the inclusion criteria, this is possible within the interview design.

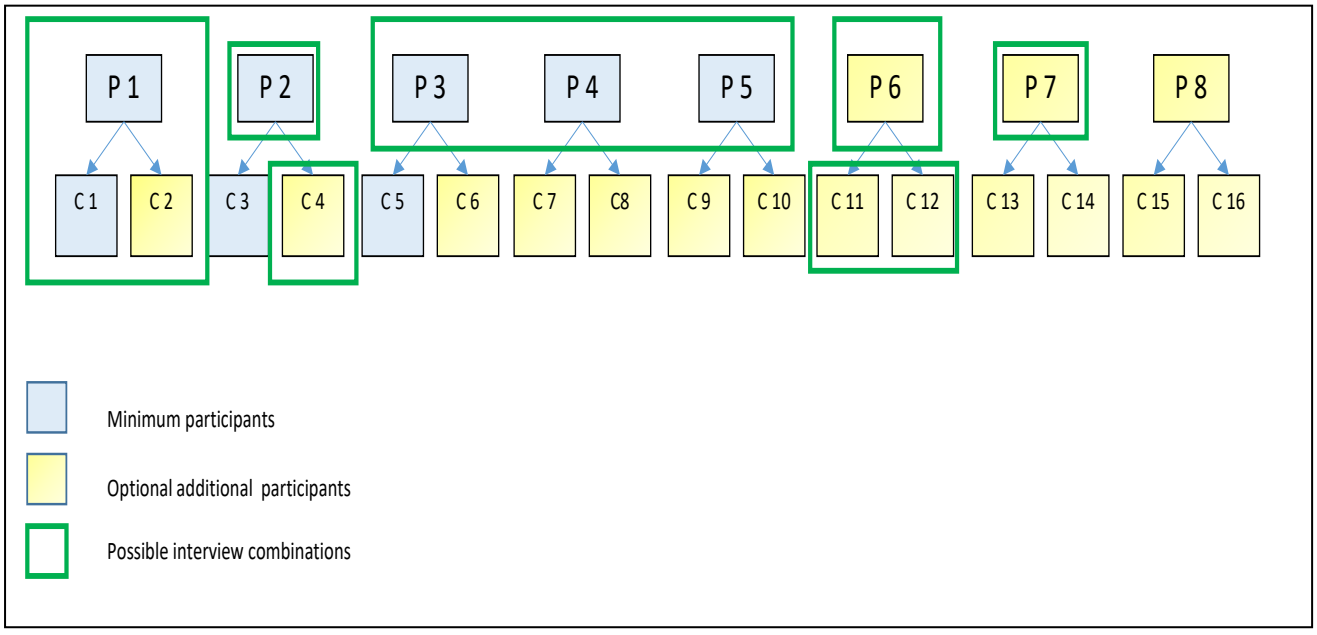

Fig.1 Possible interview combinations

2. A series of 3 sets of 2 x co-design workshops. All participants have limitations on their time – either due to personal health, carer responsibilities or clinical commitments, so the co-design process has been designed to maximise the number of people who can participate, through minimising the time commitment required to attendance at two workshops. Patients, informal care network members and clinical staff from mental health, palliative/end of life staff and relevant partner organisations (e.g. care home and primary care staff) will be invited to take part in the co-design workshops as per the inclusion and exclusion criteria below. Workshops will be facilitated by the researcher and a co-facilitator from Coventry University and will use creative methods to enhance and stimulate discussion and collaboration.

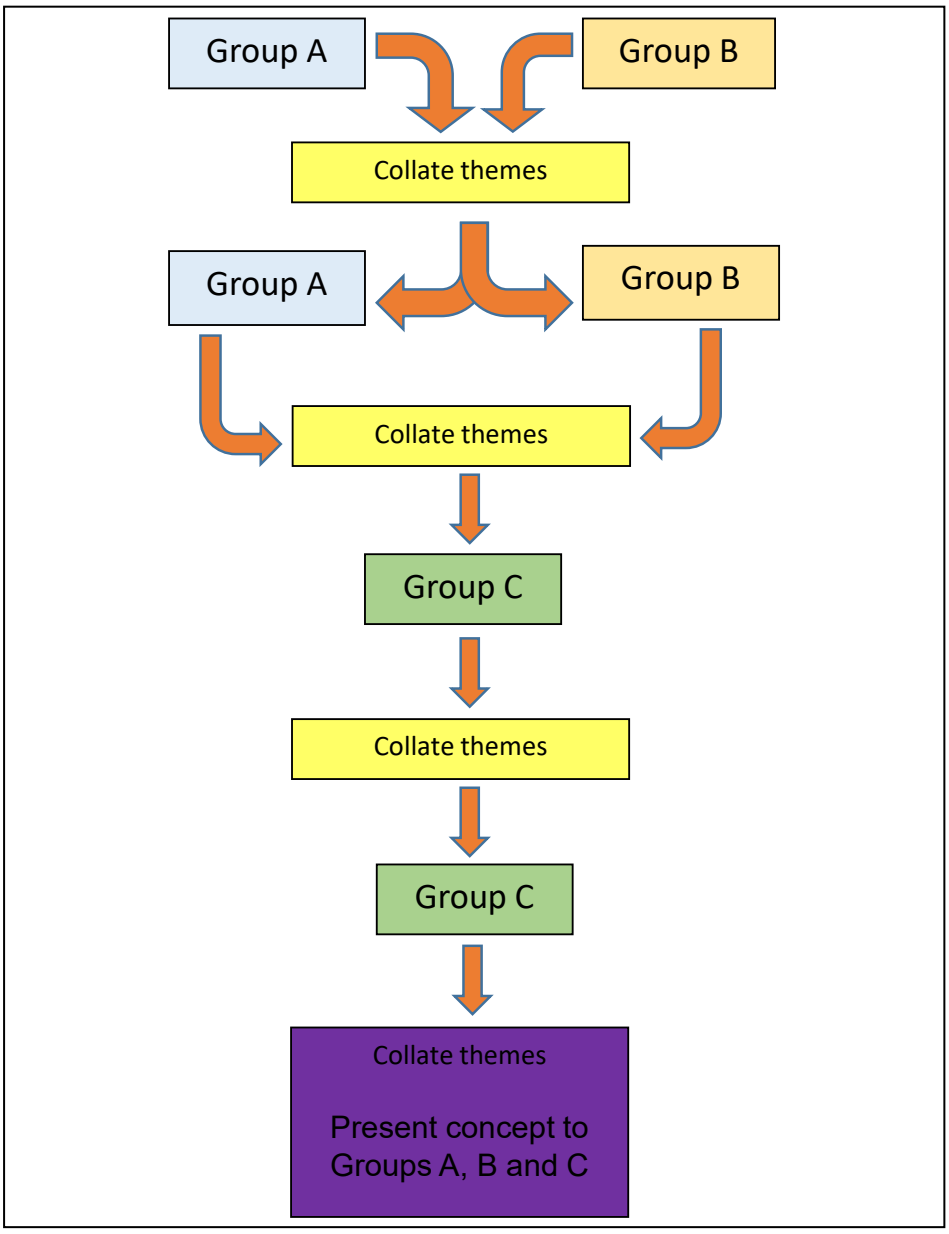

Fig. 2 Co-design process

The first workshops will involve a short presentation of what is currently known about delivering end of life care to people with severe mental illness. Findings from previous studies including a summary of the published literature will be

presented. This will act as a starting point for the group to begin to discuss and share their views about what an intervention or resource might contain, how it might be formatted and made available to staff, whether it would be useful for staff *and patients*, and other questions and themes generated by the group.

The second workshops will involve presenting a summary of the first workshop data back to the group for further discussion. Depending on the outcomes from the first workshop, the researcher will provide examples of interventions and resources developed in related areas of clinical practice to further stimulate debate and discussion. Participants will be encouraged to develop their ideas further.

The third workshop will involve the researcher presenting the themes from the first two rounds to a third group of participants. This group will be asked to consider the progress so far and think about additions and amendments, further thoughts views, issues arising and refining of the concept further. The researcher will then collate themes again and present back to the third group in a fourth and final workshop.

Finally, all participants will be invited to a presentation of the co-designed concept and content developed. The presentation will form the fifth and final stage of the co-design process and will involve use of similar creative methods to gain final comments and views.

The process will be documented by photographing group processes and outputs, annotating documents and images and completing field notes and a reflective journal. Art and design materials will be made available to the groups in each workshop and the objects and artefacts created together with field notes and observations will form the data which will be analysed by the researcher.

Location of Interviews and of Co-Design Groups

The researcher's employing organisations have agreed to provide rooms for interviews and workshops as required. Patient participants can also be interviewed at home if appropriate. The researcher has a valid DBS in place and will work to the University and employing organisations guidelines for lone working and home visits.

If appropriate, co-design workshops could also be run from alternative locations such as partner organisations. Both patients and clinical staff have limitations on their availability and ability to travel, so workshops will need to be held as locally as possible.

Identifying Participants

The researcher is employed in a large mental health trust (MHT) and a hospice and has access to groups of clinicians and patients via both sites. Approval to approach patients, carers and staff to invite them to participate in the research will be obtained from the Research and Innovation Department at the MHT and the Clinical Governance Committee of the hospice. Both organisations have provided Executive Director level sponsorship of the research study (see Appendix 2).

Patients will be recruited through both organisations by a variety of means – through the patient involvement group at the MHT, via clinical staff disseminating information at both organisations, through posters in waiting areas and through the patient newsletter at the MHT.

Other partner organisations (neighbouring hospices, mental health trusts, GP practices and voluntary sector mental health organisations) have expressed an interest in participating. Posters and leaflets will be sent by post to be displayed in waiting areas as appropriate to each organisation. A call for participants will also be made through social media local professional and user networks used by the researcher (through Twitter and Facebook) and posters sent to local community support organisations for people with mental health problems (MIND, ReThink other local voluntary and community sector organisations). The patient group can be hard to identify and engage with so a wide-reaching approach to recruitment is desirable.

Participants will be invited to make contact via direct message or email. The researcher will arrange a time to speak with the participant by telephone to screen interested participants against the inclusion criteria. The participant will then be sent further information (letter of introduction, participant information sheet and consent forms – see Appendix 3).

Patients will be asked for written consent for the researcher to inform their care co-ordinator about their participation in the research study, partly to ensure inclusion criteria regarding mental health history are met, to assess mental capacity and manage any risks from the participant taking part in the research and to ensure any known risks from the patient can be managed in the research process.

Sample

The researcher aims to carry out between 4 and 8 semi-structured interviews of approximately 60 minutes with patient participants, and up to two members of their informal care network. Flexibility is needed to allow participants to be interviewed alone, or in with their informal care members (see Fig.1). The needs of the patient, in terms of requiring or preferring someone else to be present have been built into the study design. Between 4 and 6 carers will also be interviewed, where the patient has died or is too unwell to participate.

Some patients may prefer to be interviewed in a small group with another patient or members of their informal care network. Decisions on who will be interviewed in addition to the patient, will be agreed initially with the patient by the researcher. Group interviews will only take place with the consent off all participants. The views of members of the patient's informal care network are important as carers views are also largely absent from the existing body of research. Limitations of time and budget will restrict the sample size, as will the scope of a doctoral study. Final interview sample will involve between 8 -24 depending on the number of group interviews and whether patient participants suggest members of their care network who they wish to invite to participate.

Co-design workshops can run with a wide range of participant numbers. The aim is to recruit 3 groups of between 10 and 15 participants to allow a range of backgrounds of patients and clinical staff to participate (see Fig. 2). Participants can be split into smaller sub-groups within the workshops as the material discussed can be sensitive

and sometimes difficult to share in a large group. Workshops will run for two hours with small, regular breaks, to accommodate the health needs of patient participants as appropriate.

Assessing Mental Capacity

The study aims to recruit participants who have mental capacity. It is not the aim of the study to include participants who lack mental capacity. However, the nature of the patient group means that some participants may have fluctuating capacity, and some participants who lack capacity may inquire about the study or may be highlighted by other professionals for consideration in the study.

It will therefore be necessary for the researcher to assess mental capacity at recruitment and possibly during the period of the research study.

The Mental Capacity Act 2005 (Section 3) (MCA) states that the starting point in assessing mental capacity is to assume the person has capacity. It places a duty on others to prove that someone does not have capacity. Mental capacity is defined as the ability to make a specific decision and the MCA defines four elements of a decision:

> A person needs to – understand the information relevant to the decision, retain the information for long enough to make the decision, weigh the information relevant to the decision and communicate the decision by any means (which allows people with no/limited speech to communicate in writing or by gesture.

In the context of this research study, the specific decision would be to participate in an interview or attend a workshop. Participants will need to understand the nature of the interview and the workshop, the aims of the study and the ways in which their data will be used and shared.

The Act sets out a two-stage test of capacity:

1. Does the person have an impairment of, or a disturbance in the functioning of, their mind or brain?
2. Does the impairment or disturbance mean that the person is unable to make a specific decision when they need to?

The Act states that the person who should assess capacity is the person who is involved with the person at the time the decision needs to be made. The researcher will assess capacity of potential participants in partnership with the person's care co-ordinator, through discussion with the participant about the nature of the study and their involvement, checking that the participant appears to understand. Consent to consult the participant's care co-ordinator will be sought, and if granted, the researcher will inform the care co-ordinator and ask if there is any reason the participant should not take part in the study, allowing any concerns about capacity to be discussed. If the person is detained under the Mental Health Act, the researcher will seek clarification on capacity from the Care Co-ordinator before progressing. If the participant has a diagnosis of a life-limiting condition which may affect capacity or co-morbid substance dependencies, the researcher will discuss with the participant how these may impact on their ability to take part in the research study. If the participant is being interviewed with members of the informal care network, there will be opportunity for those carers to raise concerns about capacity with the researcher if appropriate.

Consent

Written consent will be sought from all participants before they commence involvement in the research. A written consent form has been prepared in addition to the participant information sheets (see Appendix 3). Participants will be made aware that participation is voluntary and that they can withdraw at any time without explanation.

Participants will be able to withdraw their data for up to 14 days after their interview, before data analysis takes place but will be advised that once the data has been analysed that their data will not be able to be extracted. Participants will be advised that all data is anonymised.

Participants who attend co-design groups will be informed that should they choose to withdraw from the study, their data will still be included as it is not possible to withdraw individual contributions to a group discussion reliably.

Inclusion Criteria and Exclusion Criteria for Interviews

Included:

- Adults who have a diagnosis of a mental illness and are patients within mental health services. Diagnoses may include psychosis, schizophrenia, depression, personality disorder, bi-polar disorder, and anxiety disorders, which cause the patient to be cared for in mental health services; and a diagnosis of a co-existing life-limiting or terminal illness. Individual conditions would be too numerous to list, but conditions which can be expected to shorten life which may include cancers, heart disease and lung diseases including COPD, neurological conditions such as multiple sclerosis and motor neurone disease and other life-limiting and terminal conditions.
- Members of patient participant's informal care network (as agreed with the patient) will be invited to take part. This could include family members, close friends, a neighbour, work colleague or member of a faith community who is involved in the care and support of the patient.
- Carers of patients who meet the above criteria but who have already died or are too unwell to participate in the study.
- Able to give written informed consent to take part in the research

Excluded:

- Patients whose mental ill health is managed solely within primary care. Patients who have developed mental illnesses such as anxiety and depression *following* terminal illness diagnosis.
- Patients who have never been cared for in mental health services. Patients without a life-limiting or terminal diagnosis.
- Patients who unable to give informed consent or who lack mental capacity or who are unable to participate in structured interviews by reason of detention in services or where participation would cause harm or risk of relapse.
- Patients with no experience of the subject matter of the research.
- Patients whose only diagnosis is dementia.
- Paid care staff or professionals involved in the patient's care and support.

Inclusion Criteria and Exclusion Criteria for Co-Design Groups

Included:

- Patients eligible for inclusion based on criteria for interviews and in addition, members of their informal care network.
- Family members or carers of deceased patients, or those too unwell to take part, who would have met the criteria for inclusion in interviews.
- Clinicians from mental health services. Clinicians from palliative care or end of life care services (community, hospital or inpatient).
- Other clinical staff who have contact with patients who meet the criteria for interviews, such as care home staff or primary care staff.
- Able to give written informed consent to take part

Excluded:

- Participants who are unable to consent to participate, lack mental capacity or who are unable to attend the location of the co-design groups.
- Patients, family members, carers or clinical staff who have no experience or contact with the patient cohort the research study concerns.
- Patients, family members or carers, clinical staff whose only diagnosis or experience is dementia.

NB Patients with a history of mental illness may also develop forms of dementia, which is itself a life-limiting condition and can be included in this study. The study concerns the end of life care needs of people with severe mental illness and who have experience of being patients of mental health services for a sustained period. Patients whose sole diagnosis is dementia are not the primary focus for this study, although it is acknowledged that the findings may have some relevance to the end of life care needs of people with dementia.

Data Collection

Interviews will be carried out in a location convenient to the participant. This may be their home, a clinical setting or a neutral meeting place, such as a support organisation, subject to obtaining the permission of the organisation. A quiet, confidential room will be required where interviews will not be interrupted. This will be negotiated between the participant and the researcher. Limitations of time, travel cost and safety will apply. The researcher will follow the employing organisation lone-working policy when arranging visits and inform research supervisor regarding location, time and safe return. Participants care co-ordinator will be informed with prior consent by the participant.

Interviews will be audio recorded to aid verbatim transcription. The researcher will have pens and paper available for himself and the participant to aid discussion, in case use of imagery is helpful. Any artefacts created will be photographed and form part of the data to be analysed. The interviews will run for approximately 60 minutes, with breaks if required by the participant. The participant will have agreed with the researcher who else may be present during the interview, and each person will be identified in the transcripts by an initial.

Co-design groups will run for two hours with breaks. Both patients and clinical staff find it difficult to travel long distances, so the University will not be used. The researcher's employing organisation and partner agencies have offered to provide

rooms for the co-design workshops as contributions in kind. Groups will be run in non-clinical areas and other patients and staff will not be present in the spaces used to run the workshops.

Art and design materials will be used to stimulate discussion and images and artefacts created together with field notes and observations will form the data which will be analysed by the researcher.

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Data Analysis

Interviews will be transcribed verbatim and a Classic Analysis approach will be used (Kreuger and Casey, 2015) to analyse the transcripts. Transcripts will be analysed manually rather than by computer programme to allow immersion in the data and themes will be identified, grouped and summarised – using participant quotes to illustrate themes. The classic data analysis strategy also allows themes to be identified not only by frequency, but also by significance, depth or significance of comment.

There is limited research published about the process of analysing co-design data. However, the approach described by Ward et al. (2015) outlines how workshop data can be robustly analysed using a classic analysis approach. It is not possible to capture the range of discussions, comments, and non-verbal content of a co-design group by audio or even video recording as simultaneous discussions and activities take place within the workshop, so a tool which allows for analysis of the objects, images and artefacts created in the workshops is important. In addition, researcher/facilitator annotations, field notes and reflective notes can also be included in the analysis process. Analysis of the products of the co-design workshops will be carried out manually by the researcher. The second researcher/facilitator and supervisory team will review the analysis to ensure rigour and reduce researcher bias.

This approach allows the range of data this study will collect to be analysed – including visual images and artefacts as well as interview and transcripts. It allows themes to be identified and illustrated with participant's quotes and visual images, ensuring the themes remain closely linked to the original transcript and discussion.

Reflective and Reflexive Notes

A reflective journal will be kept throughout the research detailing reflections on the process including literature searching, ethics applications, discussions of research methods, sampling and data analysis, PPI opportunities and feedback, supervision meetings and discussions with other stakeholders. Text and image will be used in the journal to aid reflection and reflexivity.

Field notes, including a separate log of interviews and co-design groups will also be kept. Both documents will be anonymised and no participant will be identifiable in the journal.

Ethical Considerations and Approvals

Discussions regarding the end of life, death and dying as well as identifying barriers to delivering good care may be emotive for all participants. Participants will be reminded at the beginning of interviews and co-design groups that discussions will remain confidential and that they can withdraw at any time. The researcher is a qualified Art Psychotherapist and has eight years experience in working with individuals and running groups where emotive themes emerge in mental health, end of life care and hospice settings.

Interviews will be conducted in a setting the participant feels comfortable in – which could be at home, in a service setting or neutral space by agreement between the participant and researcher. The co-design groups will be run in an informal and discursive style. Pens and paper and envelopes will be made available for participants

to record any comments they do not feel comfortable sharing in the wider group. Interview and group participants will be provided with a debriefing sheet including the details of appropriate support services, should they feel the need to access it following the interview or workshop. Patient participants will be encouraged to contact their care co-ordinator or other support networks. Staff participants will be encouraged to use supervision and organisational staff support services if required.

Ethical approval will be sought from Coventry University and the Health Research Authority (HRA) and attached when obtained in Appendix 4.

BSMHFT Research and Innovation Department approval and John Taylor Hospice Clinical Governance Committee/CEO approval will be obtained in writing (to be attached in Appendix 4).

Confidentiality

No patient, carer, family member, clinician or service provider will be identifiable in the transcripts of interviews or other data collected for analysis. All transcripts and data sources will be anonymised. If a name is mentioned in an interview, this will not be recorded in the transcript or used within the research study.

Documents will be stored on the researcher's Coventry University password protected secure drive. Workshop notes and interview transcripts will be password protected and also stored on the researcher's Coventry University secure drive. Recordings of interviews will be destroyed once transcribed.

Resources and Costs

- Travel to interviews – researcher funded
- Travel costs for participants – reasonable travel costs will be reimbursed
- Stationary and postage – contributed in kind by BSMHFT
- Digital recording equipment – loan from CTEHR
- Meeting rooms – contributions in kind from participating organisations
- Refreshments – researcher funded or contributions in kind if possible

Coventry University have made a small amount of funding available (£250) and HEE have offered a small amount of funding which could be used to meet any additional costs.

Materials and Equipment

Audio equipment will be loaned from Coventry University Centre for Technology Enabled Health Research (CTEHR). Recordings will be destroyed following transcription. Transcripts will be held on a University password protected secure drive.

Art and design materials to support interviews and co-design workshops will be provided by the researcher.

Study Management

The supervisory team consists of:

Director of Studies
Professor Jane Coad
Centre for Technology Enabled Health Research
First Supervisor

First Supervisor
Diane Phimister
Associate Head of Department – Nursing, Midwifery and Healthcare Practice

Second Supervisor
Nikki Holliday
Senior Research Assistant

Centre for Technology Enabled Health Research

Advisor
Dr Gillian Ward
Reader in Occupational Therapy and Assistive Technologies
Centre for Technology Enabled Health Research

Coventry University acts as sponsor for PhD studies.

Dissemination

The study will be submitted for the award of PhD at Coventry University.

Journal articles will be submitted to various peer- reviewed journals for publication.

Research abstracts will be presented at a range of clinical and professional conferences/forums in poster and oral presentation form.

The findings will be presented to the BSMHFT Clinical Senate and other clinical forms as appropriate and to HEE and local LETC groups by invitation.

Benefits of the study

This study will add further understanding to the limited published research concerning provision of end of life care to people with long term mental health conditions. It will offer an insight into how clinical practice can be improved. It will present a co-designed concept for resource which aims to improve clinical practice.

Proposed Timeline

January – May 2017

- Carry out literature reviews
- Develop protocol with supervisory team
- Prepare and Submit Coventry University Ethics Application
- Complete IRAS and HRA Application
- Submit to BSMHFT R and I Department for Approval and JTH CGC for Approval
- Present to CU RSVP and (other patient groups if possible)
- Meet with Executive sponsor at BSMHFT and Clinical Director at JTH
- Meet with EoL Lead at HEE

April – June 2017

- Drafting background, literature review and methodology

June- October 2017

- Interview data collection (subject to ethical approval being granted)

October 2017 – December 2017

- Co-design workshops

December – March 2018

- Data analysis

April – September 2018

- Write up and submit thesis to Coventry University (schedule to be agreed)
- Write and submit for publication as per publication plan (to be agreed)

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Appendix 1 – Literature Review Strategy

Literature Review Strategy

A literature review has already been undertaken exploring the factors affecting the provision of end of life care to people with long term mental health difficulties. The findings of this search will form part of the background and context to this study.

However, there are two further areas which require review of the literature to inform the design of the research study. As very little research has been carried out in the specific area of clinical practice which the full study is concerned with, this review will look at how similar methods have been used in related fields.

Literature Review Question

There are two elements to this literature review.

1. How have co-creation methods been used to improve clinical practice in a) mental health services and b) palliative and end of life care services?

The findings of this search will give a basis for the rationale of the full study.

Search Strategy

The SPIDER (Cooke 2012) tool to help define the questions.

	Search 1
Sample	Mental health services Palliative/EOL services
Phenomena of Interest	Use of co-creation/co-design methods to improve clinical practice
Design	Research studies – co-design, EBCD, co-creation, user involvement, consultation methods Focus groups, case studies, Delphi studies?
Evaluation	Improving clinical practice, improving services, improving care, engagement with staff and patients/carers, involvement of staff and patients/carers
Research	Qualitative and Mixed methods

Search Terms

Search 1	Terms and Combinations
Mental Health	"mental health" or "psychiatric" or "mental health services" or "psychiatric services" or "secondary mental health" or "community mental health services" or "inpatient psychiatric" or "inpatient mental health"

End of Life Care	"end of life service" or "end of life care" or "hospice" or "palliative care service" or "inpatient palliative care" or "community palliative care"
Co-design Research Methods	"co-design" or "co-creation" or "Participation" or "involvement" or "experience-based" or "user involvement" or "patient involvement"
Improving Clinical Practice	"improving" or " improvement" or "service improvement" or "clinical improvement" or "clinical practice"

Databases to be searched

Healthcare databases	BNI, CINAHL, PsychInfo, Medline, Embase. SAGE Premier, Science Direct, Academic Search Complete, ACM Digital Library

Inclusion and Exclusion Criteria

Due to the many varying terms used to describe similar phenomena, multiple search terms will be used to increase the chance of identifying relevant literature. Initial criteria will be broad in relation to the type of studies. If the terms are too broad, further criteria can be applied after the first search. A manual review of results will be required, to exclude papers which are not relevant, due to the limitations of the search terms within the databases.

Included	Excluded
Studies in English	Non-english language studies will be excluded due to lack of reliable translation resource
Studies published since 2001	Research area concerns contemporary clinical practice and service environments so studies more than 15 years old will be excluded (this could be revised if too many or too few studies are identified)
Studies concerning, co-design, co-creation, staff and/or patient involvement, arts-based methods Studies concerning improving clinical practice will be included	Studies concerning non- participatory methods will be excluded; studies concerned solely with structural re-design of services will be excluded
Studies concerning mental health services in their broadest sense – including NHS and non-NHS provision, and studies published in other countries (if published in English)	Studies concerning other clinical areas will be excluded initially (this could be revised depending on first round of results)
Studies concerning services in palliative care, end of life care, working with patients with life-limiting illnesses and long term conditions (inpatient and community)	Studies concerning other clinical areas will be excluded initially (this could be revised depending on first round of results)
Research studies (could be expanded to include discussion pieces of practice notes if necessary)	Non-research studies, commentaries, practice notes, discussion papers will be excluded

Critical Appraisal Method

The Critical Appraisal Skills Programme (CASP) Qualitative Checklist (http://www.casp-uk.net/casp-tools-checklists) will be used to appraise the quality of identified studies.

This tool offers a structured approach to the appraisal of qualitative studies and will enhance the rigour of the process of identifying studies for inclusion in the review.

Summary of Data

A thematic analysis of the identified studies will be carried out (Braun and Clarke, 2006). Themes will be identified within each study and clustered into over-arching themes and concepts and summarised. This will inform the design of the full research study.

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Appendix 2 – Executive Sponsor Letters

Appendix 3 – Participant Information Sheets, Consent Forms and Letter of Introduction

Consent Form 1 Interviews

Improving End of Life Care for Adults with Severe Mental Illness: Understanding the views of patients, and their informal care networks, through co-design to improve approaches to clinical practice

Principal Investigator: Jed Jerwood
Director of Studies: Professor Jane Coad

Please **initial** box

1. I confirm that I have read and understood the Participant Information Sheet for the above study and have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and I am free to withdraw consent at any time without giving a reason. ☐
3. I understand that all data I provide will be treated as confidential, will be fully anonymised and stored securely. ☐
4. I agree to audio recording of the interview to allow for anonymised transcription. ☐
5. I agree to anonymised quotes from my interview being included in publications and research presentations. ☐
6. I agree that should any examples of professional misconduct, negligence, child or adult protection concern be disclosed during this study, that the researcher will report this information to: ☐

7. **FOR Patients Only**: I agree to the research team contacting my GP and/or Care Co-ordinator to inform them of my participation in the study. ☐

8. **FOR ALL PARTICIPANTS**: I agree to take part in Part One of this study - Interviews ☐

Name of Participant:	
Address:	**Email:** **Tel:**
Signed:	**Date:**
Name of Person Taking Consent:	
Role:	
Signature:	**Date:**

Consent Form 2 Workshops

Improving End of Life Care for Adults with Severe Mental Illness: Understanding the views of patients, and their informal care networks, through co-design to improve approaches to clinical practice

Principal Investigator: Jed Jerwood
Director of Studies: Professor Jane Coad

Please **initial** box

1. I confirm that I have read and understood the Participant Information Sheet for the above study and have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
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5. I agree to anonymised quotes from my interview being included in publications and research presentations. ☐
6. I agree that should any examples of professional misconduct, negligence, child or adult protection concern be disclosed during this study, that the researcher will report this information to: ☐

7. **FOR Patients Only**: I agree to the research team contacting my GP and/or Care Co-ordinator to inform them of my participation in the study. ☐

8. **FOR ALL PARTICIPANTS**: I agree to take part in Part Two of this study - Workshops ☐

Name of Participant:	
Address:	Email: Tel:
Signed:	Date:
Name of Person Taking Consent:	
Role:	
Signature:	Date:

Participant Information Sheet A – Patient Interviews

Improving End of Life Care for Adults with Severe Mental Illness: Understanding the views of patients, and their informal care networks, through co-design to improve approaches to clinical practice

I would like to invite you to take part in a research study which aims to improve the provision of end of life care for people who have severe mental illnesses and life-limiting or terminal conditions.

The study has two parts, and this part aims to understand the views and experiences of patients and members of their informal care network, on their end of life care needs, of accessing end of life care services, and of how care can be improved.

Part one involves participating in an interview with a researcher for up to an hour at a location convenient to you.

Part two involves attending two workshops – there is a separate information sheet about this which the researcher can provide you with if you are interested, but you do not have to participate in both parts of the study.

Definitions

What do we mean by end of life care?

End of life care is care provided to people living with a life-limiting or incurable, terminal illness and aims to help you live as well as possible during the last phase of life. It may be provided by a local hospice, hospital palliative care team, GP or other health provider. It includes management of pain and other symptoms and psychological, practical, social and spiritual support. It can be delivered in the community, in hospice, and at home.

What do we mean by severe mental illness?

There are many different definitions of, and ways of categorising, mental illness. This research concerns people with long term mental health conditions, being treated within the mental health system. You may have a diagnosis of a condition such as schizophrenia or psychosis, personality disorder, depression and anxiety and bi polar disorders. You will usually be under the care of a psychiatrist and have a care co-ordinator. You will usually attend a community mental health team.

What is an informal care network and who does it include?

Members of your informal care network may be family members, a friend, a neighbour, a colleague from work or someone from a religious or other group you attend. They will be involved in helping you with care and support. They won't be paid members of staff or professionals from your community mental health team or GP practice. You will have the opportunity to discuss who forms part of your informal care network and whether you want to invite them to participate before you attend an interview.

Before you decide whether to take part, it is important to understand why the research is being done and what it would involve for you. Please take the time to read the following information carefully, and discuss with others if you wish.

What is the purpose of the study?

The purpose of the study is to find out the views and experiences of patients and those who care for them. A previous study carried out by the researcher explored the views and experiences of clinical staff, this study aims to build upon the findings of that study and understand patient experience more fully. Patients and clinical staff will then come together to develop the content of a clinical resource aiming to improve care.

Why have I been invited?

As a person with a history of severe mental illness, and a life-limiting or terminal illness, your views and experiences are central to this research study. The researcher would like to ask you about your experiences, if any, of accessing end of life care services, any barriers you have experienced when trying access services, how you feel about your end of life care needs and your opinions about how care can be improved.

Do I have to participate on my own?

No, if you prefer to be interviewed with members of your informal care network, or in a small group of other participants who meet the inclusion criteria for the study, then please let the researcher know.

However, it is also important to know that your carers can be interviewed separately or you can choose to participate on your own and not invite anyone else to be involved.

Do I have to take part?

Participation in this research is entirely voluntary, and it is up to you whether you wish to take part. If you agree to participate, you are free to withdraw at any time without giving a reason.

What will happen if I do take part?

If you agree to take part, the researcher will contact you to arrange a time to meet with you. The meeting will take the form of an interview. The researcher will ask you some questions about your experiences and there will be time for you to tell the researcher how you feel about the care you have received, the barriers you may have experienced

in accessing care and your views about how end of life care for people with severe and enduring mental illnesses could be improved.

You will be asked to provide verbal and written consent to participate. The researcher will ask your permission to inform your GP and/or Care Co-ordinator of your participation in the research study. This is to ensure that the people involved in your care know you are a participant in a research study, the nature of the study and that the research study does not involve any changes to your care. In addition, the researcher will check that you meet the criteria for the study and if your GP or care co-ordinator have any concerns about you taking part in the study. This is to ensure your well-being and safety are protected.

The interview length will depend on how much you want to share, but it is expected to be about an hour. You can discuss who else you would like to involve with the researcher prior to agreeing to participate.

The interview will, with your consent, be recorded. This will allow the interview to be transcribed (written out) afterwards and enable the researcher to analyse the interview for the research study. An external company may be used to transcribe some interview data. Your identity, as well as the contents of the interview, will be kept completely confidential. Any personal information provided will be not be included and you won't be able to be identified in the study or anything published about the results. At the end of the research study, any identifiable personal data will be disposed of by the researcher. No personal information will be held by the researcher of the University after the research study concludes.

In the interview, in addition to talking with the researcher, you will have the opportunity to write down or draw any thoughts, images or experiences you don't feel comfortable sharing if you prefer. Pens and paper will be made available for this.

Refreshments will be provided if you attend an interview outside your home. Please let the researcher know if you have any specific dietary requirements such as no dairy, gluten-free etc.

At the end of the interview, the researcher will ask you if you would like to take part in the second part of the study and attend the workshops. You do not have to take part in these and participation in the second part of the study is also entirely voluntary. Further information about the second part will be provided by the researcher.

Assessing Mental Capacity

The Mental Capacity Act 2005 (Section 3) (MCA) states that the starting point in assessing mental capacity is to assume the person has capacity. It places a duty on others to prove that someone does not have capacity to make a specific decision. In the context of this research study, the specific decision would be to participate in an interview or attend a workshop.

The researcher will explain the nature of the research study to you before you agree to take part. They will ask you if you understand why the research is being carried out,

what participating involves and if you agree to participate. If they have any concerns about your mental capacity, they will discuss this with you and your care co-ordinator.

Travel Expenses

If you take part in an interview, the researcher will offer to interview you at your home.

If you do not feel comfortable with this and prefer to meet at another convenient location, which requires you to travel, the equivalent of bus or standard train fare can be claimed to cover reasonable travel expenses. The researcher will provide you with a form to claim expenses.

What are the possible benefits of taking part?

There are no financial rewards for taking part. However, your views and experiences will shape the findings of this research, which will inform future practice and also inform the design of the next stage of the study. The findings of the research may inform the development of teaching and learning resources, good practice guidelines, policies and procedures for clinical staff and service managers. The findings will also be fed into the development of national policy and practice developments.

The findings will be submitted for publication in journals and submitted to Coventry University as part of the researcher's PhD thesis.

What support is available to me if I find participation upsetting?

Talking about death and dying, palliative and end of life care, and mental health issues, may be upsetting for some people. No assumptions will be made about your personal experiences. You will be provided with the contact details of local support services available. Your care co-ordinator will be made aware of your participation in the study if you give consent. There will be time at the end of the interview for de-briefing and discussion with you. The researcher is a qualified Art Psychotherapist, employed by Birmingham and Solihull Mental Health Trust and registered with Health and Care Professions Council (HCPC). The researcher has experience and understanding of complex mental health issues and the support available to any participant who may become distressed.

Will my taking part in the study be kept confidential?

Yes. The researcher will ensure that the contents of every interview remain confidential and that any personal information provided is kept fully anonymised. Your identity, as well as the contents of the interview, will be kept completely confidential. Any personal information provided will be not be included and you won't be able to be identified in the study or anything published about the results.

What will happen if I change my mind?

Participation in this study is entirely voluntary and you are free to withdraw from the study at any time without giving a reason.

Your care will not be impacted upon in any negative way if you chose not to participate or withdraw from participation at any time.

You may withdraw consent at any point in the process. If you decide to withdraw within 14 days of being interviewed, data from interviews will be withdrawn from the study. However, if you decide to withdraw after this time, it will not be possible to extract your data as it will have been analysed by the researcher. However, you will not be identifiable in any results of papers published by the researcher.

What if there is a problem?

Will my data be kept confidential?

Yes. All data collected will be fully anonymised and confidential. Recordings of interviews will be destroyed following transcription. Anonymised transcripts will be kept securely and password protected on a University secure drive.

What will happen to the results of the study?

The results will be written up by the researcher, Jed Jerwood for the award of PhD in Clinical Research from Coventry University. The thesis will be stored at Coventry University library. The results will also be submitted for publication in a peer-reviewed journal, will be presented within the researcher's employing organisations and professional networks and at professional conferences.

Who is organising and funding the research?

Jed Jerwood is organising the research, under the supervision of Professor Jane Coad as part of doctoral research programme at the Centre for Technology Enabled Health Research at Coventry University. The research is funded by Coventry University,

Birmingham and Solihull Mental Health Trust Research and Innovation Department and Health Education England.

Contact details:
Jed Jerwood
Doctoral Research Student

Participant Information Sheet B – Workshops (for Patient Participants)

Improving End of Life Care for Adults with Severe Mental Illness: Understanding the views of patients, and their informal care networks, through co-design to improve approaches to clinical practice

I would like to invite you to take part in the second part of a research study which aims to improve the provision of end of life care for people who have severe mental illnesses and life-limiting or terminal conditions.

It involves attending two workshops with other patients, carers and family members and clinical staff, to develop the content of an information/education resource which aims to improve care.

Definitions

What do we mean by end of life care?

End of life care is care provided to people living with a life-limiting or incurable, terminal illness and aims to help you live as well as possible during the last phase of life. It may be provided by a local hospice, hospital palliative care team, GP or other health provider. It includes management of pain and other symptoms and psychological, practical, social and spiritual support. It can be delivered in the community, in hospice, and at home.

What do we mean by severe mental illness?

There are many different definitions of, and ways of categorising, mental illness. This research concerns people with long term mental health conditions, being treated within the mental health system. You may have a diagnosis of a condition such as schizophrenia or psychosis, personality disorder, depression and anxiety and bi polar disorders. You will usually be under the care of a psychiatrist and have a care co-ordinator. You will usually attend a community mental health team.

What is an informal care network and who does it include?

Members of your informal care network may be family members, a friend, a neighbour, a colleague from work or someone from a religious or other group you attend. They will be involved in helping you with care and support. They won't be paid members of staff or professionals from your community mental health team or GP practice.

Before you decide whether to take part, it is important to understand why the research is being done and what it would involve for you. Please take the time to read the following information carefully, and discuss with others if you wish.

What is the purpose of the study?

The purpose of the study is to find out the views and experiences of patients and those who care for them. A previous study carried out by the researcher explored the views and experiences of clinical staff, this study aims to build upon the findings of that study and understand patient experience more fully. Patients and clinical staff will then come together to develop the content of a clinical resource aiming to improve care.

Why have I been invited?

As a person with a history of severe mental illness, and a life-limiting or terminal illness, your views and experiences are central to this research study. You are invited to take part in a process called co-design. This is a way of designing services which involves patients and families as well as staff and other partners, as equal partners in the design process. You are invited to take part in two workshops, as well as attend a presentation event at the end of the process where the results will be presented.

Who else will be there? What will happen?

If you agree to take part, the researcher will contact you to talk through the times and dates of the workshops, the time commitment and the arrangements for claiming travel expenses. They will ask you briefly about your mental and physical health. This is to make sure the right people are invited to take part in the study only. The researcher will send you a participant information sheet and a consent form to read and sign. If you need help to read the sheet and form, the researcher will make a time to meet with you and help you with this.

You will be asked to provide verbal and written consent to participate in the study. The researcher will ask your permission to inform your GP and/or Care Co-ordinator of your participation in the research study. This is to ensure that the people involved in your care know you are a participant in a research study, the nature of the study and that the research study does not involve any changes to your care. . In addition, the researcher will check that you meet the criteria for the study and if your GP or care co-ordinator have any concerns about you taking part in the study. This is to ensure your well-being and safety are protected.

You are asked to commit to attend two workshops. It is important to try and attend both workshops where possible. The researcher will give you dates and time for both workshops before you agree to take part.

There will be other patients, family members and carers and clinical staff from different organisations present. Everybody who has been invited to take part has experience of living with mental ill health and life-limiting conditions, or working with people who do. There will be no more than 15 people in each workshop.

You will be asked to think about developing a resource for clinical staff and patients which aims to provide information, resources, including patient stories, and other information which you feel is important. The format of the resource will be discussed. You will be asked to contribute verbally, but also through drawing, writing, using images and objects and discussion to generate debate and thinking. There will be lots of different ways to contribute, but no-one will be made to participate in a way which makes them feel uncomfortable. The facilitators will ensure everyone has chance to speak, to participate and to contribute, regardless of their role within the group.

Groups will be hosted by the researcher, who you will have met, and a colleague from Coventry University, experienced in running workshops. The workshops will last two hours, but will include regular breaks and refreshments.

The researcher and co-facilitator will photograph the written, drawn and other objects created in the workshops to aid the analysis of the content of the workshop. No images will be taken of participants faces and you will not be identifiable in the photographs.

Photographs of the data may be used to illustrate journal articles, but again, participants will not be identifiable in any photographs used. Photographs will be used to illustrate the process of the research and the data collected.

Do I have to take part?

No, participation in this research is entirely voluntary, and it is up to you whether you wish to take part. If you agree to participate, you are free to withdraw at any time without giving a reason.

Assessing Mental Capacity

The Mental Capacity Act 2005 (Section 3) (MCA) states that the starting point in assessing mental capacity is to assume the person has capacity. It places a duty on others to prove that someone does not have capacity to make a specific decision. In the context of this research study, the specific decision would be to participate in an interview or attend a workshop.

The researcher will explain the nature of the research study to you before you agree to take part. They will ask you if you understand why the research is being carried out, what participating involves and if you agree to participate. If they have any concerns about your mental capacity, they will discuss this with you and your care co-ordinator.

Travel Expenses

If you take part in the workshops, the equivalent of bus or standard train fare can be claimed to cover reasonable travel expenses. The researcher will provide you with a form to claim expenses.

What are the possible benefits of taking part?

There are no financial rewards for taking part. However, your views and experiences will shape the findings of this research, which will inform future practice and care. The

findings of the research may inform the development of teaching and learning resources, good practice guidelines, policies and procedures for clinical staff and service managers. The findings will also be fed into the development of national policy and practice developments.

The findings will be submitted for publication in journals and submitted to Coventry University as part of the researcher's PhD thesis.

What support is available to me if I find participation upsetting?

Talking about death and dying, palliative and end of life care, and mental health issues, may be upsetting for some people. No assumptions will be made about yours personal experiences. You will be provided with the contact details of local support services available. Your care co-ordinator will be made aware of your participation in the study if you give consent. There will be time at the end of the interview for de-briefing and discussion with you. The researcher is a qualified Art Psychotherapist, employed by Birmingham and Solihull Mental Health Trust and registered with Health and Care Professions Council (HCPC). The researcher has experience and understanding of complex mental health issues and the support available to any participant who may become distressed.

Will my taking part in the study be kept confidential?

Yes. The researcher will ensure that the contents of every workshop remain confidential and that any personal information provided is kept fully anonymised. Your identity, as well as the contents of the workshop, will be kept completely confidential. Any personal information provided will be not be included and you won't be able to be identified in the study or anything published about the results.

At the end of the research study, any identifiable personal data will be disposed of by the researcher. No personal information will be held by the researcher of the University after the research study concludes.

What will happen if I change my mind?

Participation in this study is entirely voluntary and you are free to withdraw from the study at any time without giving a reason.

Your care will not be impacted upon in any negative way if you chose not to participate or withdraw from participation at any time.

You may withdraw from the study at any point in the process. However, if you decide to withdraw after participating in either of the workshops, your contributions to the workshops won't be able to be removed. However, you will not be identifiable in any results of papers published by the researcher.

What if there is a problem?

Insurance and indemnity cover for this study is provided as part of ethical approval by Coventry University. Every care to ensure the safety and well-being of participants will be taken during this research study. However, in the unlikely event that you are injured by taking part, compensation may be available. If you suspect that the injury is the result of the Sponsor's or the NHS Trust's negligence then you may be able to claim compensation. Please contact the Chief Investigator Jed Jerwood jerwoodj@uni.coventry.ac.uk for further details.

Will my data be kept confidential?

Yes. All data collected will be fully anonymised and confidential and stored on a secure password protected University drive. Images, objects and artefacts created in the workshops will be photographed and secured as described and the originals items disposed of securely.

Some materials have been removed from this thesis due to Third Party Copyright. Pages where material has been removed are clearly marked in the electronic version. The unabridged version of the thesis can be viewed at the Lanchester Library, Coventry University

What will happen to the results of the study?

The results will be written up by the researcher, Jed Jerwood for the award of PhD in Clinical Research from Coventry University. The thesis will be stored at Coventry University library. The results will also be submitted for publication in a peer-reviewed journal, will be presented within the researcher's employing organisations and professional networks and at professional conferences.

Who is organising and funding the research?

Jed Jerwood is organising the research, under the supervision of Professor Jane Coad as part of doctoral research programme at the Centre for Technology Enabled Health Research at Coventry University. The research is funded by Coventry University, Birmingham and Solihull Mental Health Trust Research and Innovation Department and Health Education England.

Contact details:
Jed Jerwood

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Participant Information Sheet C – Carer Interviews

Improving End of Life Care for Adults with Severe Mental Illness: Understanding the views of patients, and their informal care networks, through co-design to improve approaches to clinical practice

I would like to invite you to take part in a research study which aims to improve the provision of end of life care for people who have severe mental illnesses and life-limiting or terminal conditions.

You have been invited to take part because …….has agreed to take part in the study and identified you as a someone who helps care and support them.

The study has two parts, and this part aims to understand the views and experiences of patients, and members of their informal care network, on their end of life care needs, of accessing end of life care services, and of how care can be improved.

It involves participating in an interview with a researcher for up to an hour at a location and time convenient to you. You may be invited to take part in an interview with…….or on your own. This will be agreed between you, the patient participant and the researcher.

What do we mean by end of life care?

End of life care is care provided to people living with a life-limiting or incurable, terminal illness and aims to help people live as well as possible during the last phase of life. It may be provided by a local hospice, hospital palliative care team, GP or other health provider. It includes management of pain and other symptoms and psychological, practical, social and spiritual support. It can be delivered in the community, in hospice, and at home.

What do we mean by severe mental illness?

There are many different definitions of, and ways of categorising, mental illness. This research concerns people with long term mental health conditions, being treated within the mental health system. The person you help to care for may have a diagnosis of a condition such as schizophrenia or psychosis, personality disorder, depression and anxiety and bi polar disorders. They will usually be under the care of a psychiatrist and have a care co-ordinator. They will usually attend a community mental health team.

What is an informal care network and who does it include?

Members of a patient's informal care network may be family members, a friend, a neighbour, a colleague from work or someone from a religious or other group. They will be involved in helping with care and support. They won't be paid members of staff or professionals from a community mental health team or GP practice.

Before you decide whether to take part, it is important to understand why the research is being done and what it would involve for you. Please take the time to read the following information carefully, and discuss with others if you wish.

What is the purpose of the study?

The purpose of the study is to find out the views and experiences of patients and those who care for them. A previous study carried out by the researcher explored the views and experiences of clinical staff, this study aims to build upon the findings of that study and understand patient experience more fully. Patients and clinical staff will then come together to develop the content of a clinical resource aiming to improve care.

Why have I been invited?

As someone who helps care and support a person with a history of severe mental illness, and a life-limiting or terminal illness, your views and experiences are central to this research study. The researcher would like to ask you about your experiences, if any, of supporting access to end of life care services, any barriers you have experienced when trying access services, how you feel about the end of life care needs of the person you support and your opinions about how care can be improved.

Do I have to take part?

Participation in this research is entirely voluntary, and it is up to you whether you wish to take part. If you agree to participate, you are free to withdraw at any time without giving a reason. This has been explained to the person you help to care for.

What will happen if I do take part?

If you agree to take part, the researcher will contact you to arrange a time to meet with you. The meeting will take the form of a semi-structured interview. The researcher will ask you some questions about your experiences and there will be time for you to tell the researcher your experiences and observations about the end of life care available to the person you help to support, how you feel about the care they have received, the barriers you may have experienced in accessing care and your views about how end of life care for people with severe and enduring mental illnesses could be improved.

You will be asked to provide verbal and written consent to participate. The interview length will depend on how much you want to share, but it is expected to be about an hour. Before interviews are agreed, you will have chance to discuss whether you want to be interviewed on your own or with the person you help to support, with the researcher.

The interview will, with your consent, be recorded. This will allow the interview to be transcribed (written out) afterwards and enable the researcher to analyse the interview for the research study. An external company may be used to transcribe some interview data. Your identity, as well as the contents of the interview, will be kept completely confidential. Any personal information provided will be fully anonymised.

In the interview, in addition to talking with the researcher, you will have the opportunity to write down or draw any thoughts, images or experiences you don't feel comfortable sharing if you prefer. Pens and paper will be made available for this.

Refreshments will be provided if you attend an interview outside your home. Please let the researcher know if you have any specific dietary requirements such as no dairy, gluten-free etc.

At the end of the interview, the researcher will ask you if you would like to take part in the second part of the study and attend the workshops. You do not have to take part in these and participation in the second part of the study is also entirely voluntary.

Travel Expenses

If you take part in an interview, the researcher will offer to interview you at your home.

If you do not feel comfortable with this and prefer to meet at another convenient location, which requires you to travel, the equivalent of bus or standard train fare can be claimed to cover reasonable travel expenses. The researcher will provide you with a form to claim expenses.

What are the possible benefits of taking part?

There are no financial rewards for taking part. However, your views and experiences will shape the findings of this research, which will inform future practice and also inform the design of the next stage of the study. The findings of the research may inform the development of teaching and learning resources, good practice guidelines, policies and procedures for clinical staff and service managers. The findings will also be fed into the development of national policy and practice developments.

The findings will be submitted for publication in a peer-reviewed journal and submitted to Coventry University as part of the researcher's PhD thesis.

What support is available to me if I find participation upsetting?

Talking about death and dying, palliative and end of life care, and mental health issues, may be upsetting for some people. No assumptions will be made about your personal experiences. You will be provided with the contact details of local support services available. There will be time at the end of the interview for de-briefing and discussion with you. The researcher is a qualified Art Psychotherapist, employed by Birmingham and Solihull Mental Health Trust and registered with HCPC. The researcher has experience and understanding of complex mental health issues and the support available to any participant who may become distressed.

Will my taking part in the study be kept confidential?

Yes. The researcher will ensure that the contents of every interview remain confidential and that any personal information provided is kept fully anonymised. Ethical and legal practice will be followed.

At the end of the research study, any identifiable personal data will be disposed of by the researcher. No personal information will be held by the researcher of the University after the research study concludes.

What will happen if I change my mind?

Participation in this study is entirely voluntary and you are free to withdraw from the study at any time without giving a reason.

You may withdraw consent at any point in the process. Data from interviews will be withdrawn from the study. However, if you have participated in a workshop it will not be possible to withdraw your individual contributions to a group discussion.

What if there is a problem?

Will my data be kept confidential?

Yes. All data collected will be fully anonymised and confidential. Recordings of interviews will be destroyed following transcription. Anonymised transcripts will be kept securely and password protected on a University secure drive.

Although not anticipated, should any examples of professional misconduct, negligence, adult or child safe-guarding concern be disclosed, the researcher is

What will happen to the results of the study?

The results will be written up by Jed Jerwood as a thesis to be submitted for the award of PhD in Clinical Research from Coventry University. The thesis will be stored at Coventry University library. The results will also be submitted for publication in a peer-reviewed journal, will be presented within the researcher's employing organisations and professional networks and at professional conferences.

Who is organising and funding the research?

Jed Jerwood is organising the research, under the supervision of Professor Jane Coad as part of doctoral research programme at the Centre for Technology Enabled Health Research at Coventry University. The research is funded by Coventry University, Birmingham and Solihull Mental Health Trust Research and Innovation Department and Health Education England.

Contact details:
Jed Jerwood

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Participant Information Sheet D – Workshops (for Carer Participants)

Improving End of Life Care for Adults with Severe Mental Illness: Understanding the views of patients, and their informal care networks, through co-design to improve approaches to clinical practice

I would like to invite you to take part in a research study which aims to improve the provision of end of life care for people who have severe mental illnesses and life-limiting or terminal conditions.

The study has two parts, and this is the second part. The first part was a series of interviews with patients and members of their informal care network, some of whom may be participating in this second stage of the research.

This stage of the study aims to bring together patients, family member, carers, and clinical staff to develop the content of an education/information resource.

Definitions

What do we mean by end of life care?

End of life care is care provided to people living with a life-limiting or incurable, terminal illness and aims to help people live as well as possible during the last phase of life. It may be provided by a local hospice, hospital palliative care team, GP or other health provider. It includes management of pain and other symptoms and psychological, practical, social and spiritual support. It can be delivered in the community, in hospice, and at home.

What do we mean by severe mental illness?

There are many different definitions of, and ways of categorising, mental illness. This research concerns people with long term mental health conditions, being treated within the mental health system. People will usually have a diagnosis of a condition such as schizophrenia or psychosis, personality disorder, depression and anxiety and bi polar disorders. They will usually be under the care of a psychiatrist and have a care co-ordinator. They will usually attend a community mental health team.

What is an informal care network and who does it include?

Members of a patient's informal care network may be family members, a friend, a neighbour, a colleague from work or someone from a religious or other group. They

will be involved in helping with care and support. They won't be paid members of staff or professionals from a community mental health team or GP practice.

Before you decide whether to take part, it is important to understand why the research is being done and what it would involve for you. Please take the time to read the following information carefully, and discuss with others if you wish.

What is the purpose of the study?

The purpose of the study is to find out the views and experiences of patients and those who care for them. A previous study carried out by the researcher explored the views and experiences of clinical staff, this study aims to build upon the findings of that study and understand patient experience more fully. Patients and clinical staff will then come together to develop the content of a clinical resource aiming to improve care.

Why have I been invited?

As a person who helps care and support a person with a history of severe mental illness, and a life-limiting or terminal illness, your views and experiences are central to this research study. You are invited to take part in a process called co-design. This is a way of designing services which involves patients and families as well as staff and other partners, as equal partners in the design process. You are invited to take part in two workshops, as well as attend a presentation event at the end of the process where the end product will be shared.

Who else will be there? What will happen?

There will be other patients, family members and carers and clinical staff from different organisations present. Everybody who has been invited to take part has experience of living with mental ill health and life-limiting conditions, or working with people who do. There will be no more than 15 people in each workshop.

You will be asked to think about developing a resource for clinical staff and patients which aims to provide information, resources, including patient stories, and other information which you feel is important. The format of the resource will be discussed. You will be asked to contribute verbally, but also through drawing, writing, using images and objects and discussion to generate debate and thinking. There will be lots of different ways to contribute, but no-one will be made to participate in a way which makes them feel uncomfortable. The facilitators will ensure everyone has chance to speak, to participate and to contribute, regardless of their role within the group.

Groups will be hosted by the researcher and a colleague from Coventry University, experienced in running workshops. The workshops will last two hours, but will include regular breaks and refreshments.

The researcher and co-facilitator will photograph the written, drawn and other objects created in the workshops to aid the analysis of the content of the workshop. No images will be taken of participants faces and you will not be identifiable in the photographs.

Photographs of the data may be used to illustrate journal articles, but again, participants will not be identifiable in any photographs used. Photographs will be used to illustrate the process of the research and the data collected.

Do I have to take part?

Participation in this research is entirely voluntary, and it is up to you whether you wish to take part. If you agree to participate, you are free to withdraw at any time without giving a reason.

Travel Expenses

If you take part in the workshops, the equivalent of bus or standard train fare can be claimed to cover reasonable travel expenses. The researcher will provide you with a form to claim expenses.

What are the possible benefits of taking part?

There are no financial rewards for taking part. However, your views and experiences will shape the findings of this research, which will inform future practice and also inform the design of the next stage of the study. The findings of the research may inform the development of teaching and learning resources, good practice guidelines, policies and procedures for clinical staff and service managers. The findings will also be fed into the development of national policy and practice developments.

The findings will be submitted for publication in a peer-reviewed journal and submitted to Coventry University as part of the researcher's PhD thesis.

What support is available to me if I find participation upsetting?

Talking about death and dying, palliative and end of life care, and mental health issues, may be upsetting for some people. No assumptions will be made about your personal experiences. You will be provided with the contact details of local support services available. There will be time at the end of the interview for de-briefing and discussion with you. The researcher is a qualified Art Psychotherapist, employed by Birmingham and Solihull Mental Health Trust and registered with HCPC. The researcher has experience and understanding of complex mental health issues and the support available to any participant who may become distressed.

Will my taking part in the study be kept confidential?

Yes. The researcher will ensure that the contents of every interview remain confidential and that any personal information provided is kept fully anonymised. Ethical and legal practice will be followed.

At the end of the research study, any identifiable personal data will be disposed of by the researcher. No personal information will be held by the researcher of the University after the research study concludes.

What will happen if I change my mind?

Participation in this study is entirely voluntary and you are free to withdraw from the study at any time without giving a reason. However, if you have participated in a workshop it will not be possible to withdraw your individual contributions to a group discussion.

What if there is a problem?

Some materials have been removed from this thesis due to Third Party Copyright. Pages where material has been removed are clearly marked in the electronic version. The unabridged version of the thesis can be viewed at the Lanchester Library, Coventry University

Will my data be kept confidential?

Yes. All data collected will be fully anonymised and confidential. Recordings of interviews will be destroyed following transcription. Anonymised transcripts will be kept securely and password protected on a University secure drive.

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What will happen to the results of the study?

The results will be written up by Jed Jerwood as a thesis to be submitted for the award of PhD in Clinical Research from Coventry University. The thesis will be stored at Coventry University library. The results will also be submitted for publication in a peer-reviewed journal, will be presented within the researcher's employing organisations and professional networks and at professional conferences.

Who is organising and funding the research?

Jed Jerwood is organising the research, under the supervision of Professor Jane Coad as part of doctoral research programme at the Centre for Technology Enabled Health Research at Coventry University. The research is funded by Coventry University, Birmingham and Solihull Mental Health Trust Research and Innovation Department and Health Education England.

Participant Information Sheet E – Workshops (for Clinician Participants)

Improving End of Life Care for Adults with Severe Mental Illness: Understanding the views of patients, and their informal care networks, through co-design to improve approaches to clinical practice

I would like to invite you to take part in a research study which aims to improve the provision of end of life care for people who have severe mental illnesses and life-limiting or terminal conditions.

The study has two parts, and this is the second part. The first part was a series of semi-structured interviews with patients and members of their informal care network, some of whom may be participating in this second stage of the research.

This part of the study aims to bring together patients, family member, carers, and clinical staff to develop the content of an education/information resource using co-design methods.

Definitions

What do we mean by end of life care?

End of life care is care provided to people living with a life-limiting or incurable, terminal illness and aims to help people live as well as possible during the last phase of life. It may be provided by a local hospice, hospital palliative care team, GP or other health provider. It includes management of pain and other symptoms and psychological, practical, social and spiritual support. It can be delivered in the community, in hospice, and at home.

What do we mean by severe mental illness?

There are many different definitions of, and ways of categorising, mental illness. This research concerns people with long term mental health conditions, being treated within the mental health system. People will usually have a diagnosis of a condition such as schizophrenia or psychosis, personality disorder, depression and anxiety and bi polar disorders. They will usually be under the care of a psychiatrist and have a care co-ordinator. They will usually attend a community mental health team.

What is an informal care network and who does it include?

Members of a patient's informal care network may be family members, a friend, a neighbour, a colleague from work or someone from a religious or other group. They will be involved in helping with care and support. They won't be paid members of staff or professionals from a community mental health team or GP practice.

Before you decide whether to take part, it is important to understand why the research is being done and what it would involve for you. Please take the time to read the following information carefully, and discuss with others if you wish.

What is the purpose of the study?

The purpose of the study is to find out the views and experiences of patients and those who care for them. A previous study carried out by the researcher explored the views and experiences of clinical staff, this study aims to build upon the findings of that study and understand patient experience more fully. Patients and clinical staff will then come together to develop the content of a clinical resource aiming to improve care.

Why have I been invited?

As a clinician working either in mental health services or end of life services, your views and experiences are central to this research study.

Do I have to take part?

Participation in this research is entirely voluntary, and it is up to you whether you wish to take part. If you agree to participate, you are free to withdraw at any time without giving a reason.

What will happen if I do take part?

This part two involves attending a series of two workshops. It is important to attend both workshops. The researcher will provide you with dates in advance. Attendees at the workshops will be a mixture of patient participants, family members and carers, clinical staff from palliative and end of life care services, mental health staff and primary care staff.

Groups will be hosted by the researcher and a colleague from Coventry University, experienced in running workshops. The workshops will last two hours, but will include regular breaks.

You will be asked to think about the content of a resource for clinical staff and patients which aims to provide information, resources, including patient stories, and other information which you feel is important. The format of the resource will be discussed. You will be asked to contribute verbally, but also through drawing, writing, using images and objects and discussion to generate debate and thinking. There will be lots of different ways to contribute, but no-one will be made to participate in a way which makes them feel uncomfortable. The facilitators will ensure everyone has chance to speak, to participate and to contribute, regardless of their role within the group.

If you think you would like to be part of the workshops, please read and sign the consent form attached to this information sheet.

The researcher and co-facilitator will photograph the written, drawn and other objects created in the workshops to aid the analysis of the content of the workshop. No images will be taken of participants faces and you will not be identifiable in the photographs.

Photographs of the data may be used to illustrate journal articles, but again, participants will not be identifiable in any photographs used. Photographs will be used to illustrate the process of the research and the data collected.

Travel Expenses

If you take part in the workshops, the equivalent of bus or standard train fare can be claimed to cover reasonable travel expenses. The researcher will provide you with a form to claim expenses.

What are the possible benefits of taking part?

There are no financial rewards for taking part. However, your views and experiences will shape the findings of this research, which will inform future practice and also inform the design of the next stage of the study. The findings of the research may inform the development of teaching and learning resources, good practice guidelines, policies and procedures for clinical staff and service managers. The findings will also be fed into the development of national policy and practice developments.

The findings will be submitted for publication in a peer-reviewed journal and submitted to Coventry University as part of the researcher's PhD thesis.

What support is available to me if I find participation upsetting?

Talking about death and dying, palliative and end of life care, and mental health issues, may be upsetting for some people. No assumptions will be made about your personal experiences. You will be provided with the contact details of local support services available. There will be time at the end of the interview for de-briefing and discussion with you. The researcher is a qualified Art Psychotherapist, employed by Birmingham and Solihull Mental Health Trust and registered with HCPC. The researcher has experience and understanding of complex mental health issues and the support available to any participant who may become distressed.

Will my taking part in the study be kept confidential?

Yes. The researcher will ensure that the contents of every interview remain confidential and that any personal information provided is kept fully anonymised. Ethical and legal practice will be followed.

At the end of the research study, any identifiable personal data will be disposed of by the researcher. No personal information will be held by the researcher of the University after the research study concludes.

What will happen if I change my mind?

Participation in this study is entirely voluntary and you are free to withdraw from the study at any time without giving a reason. However, if you have participated in a co-design workshop it will not be possible to withdraw your individual contributions to a group discussion.

What if there is a problem?

Some materials have been removed from this thesis due to Third Party Copyright. Pages where material has been removed are clearly marked in the electronic version. The unabridged version of the thesis can be viewed at the Lanchester Library, Coventry University

Will my data be kept confidential?

Yes. All data collected will be fully anonymised and confidential. Recordings of interviews will be destroyed following transcription. Anonymised transcripts will be kept securely and password protected on a University secure drive.

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What will happen to the results of the study?

The results will be written up by Jed Jerwood as a thesis to be submitted for the award of PhD in Clinical Research from Coventry University. The thesis will be stored at Coventry University library. The results will also be submitted for publication in a peer-reviewed journal, will be presented within the researcher's employing organisations and professional networks and at professional conferences.

Who is organising and funding the research?

Jed Jerwood is organising the research, under the supervision of Professor Jane Coad as part of doctoral research programme at the Centre for Technology Enabled Health Research at Coventry University. The research is funded by Coventry University,

Birmingham and Solihull Mental Health Trust Research and Innovation Department and Health Education England.

Contact details:
Jed Jerwood

Participant Information Sheet F – Carer Interviews

Improving End of Life Care for Adults with Severe Mental Illness: Understanding the views of patients, and their informal care networks, through co-design to improve approaches to clinical practice

I would like to invite you to take part in a research study which aims to improve the provision of end of life care for people who have severe mental illnesses and life-limiting or terminal conditions.

The study has two parts, and this part aims to understand the views and experiences of patients, and members of their informal care network, on their end of life care needs, of accessing end of life care services, and of how care can be improved.

It involves participating in an interview with a researcher for up to an hour at a location and time convenient to you.

What do we mean by end of life care?

End of life care is care provided to people living with a life-limiting or incurable, terminal illness and aims to help people live as well as possible during the last phase of life. It may be provided by a local hospice, hospital palliative care team, GP or other health provider. It includes management of pain and other symptoms and psychological, practical, social and spiritual support. It can be delivered in the community, in hospice, and at home.

What do we mean by severe mental illness?

There are many different definitions of, and ways of categorising, mental illness. This research concerns people with long term mental health conditions, being treated within the mental health system. The person you help to care for may have a diagnosis of a condition such as schizophrenia or psychosis, personality disorder, depression and anxiety and bi polar disorders. They will usually be under the care of a psychiatrist and have a care co-ordinator. They will usually attend a community mental health team.

What is an informal care network and who does it include?

Members of a patient's informal care network may be family members, a friend, a neighbour, a colleague from work or someone from a religious or other group. They will be involved in helping with care and support. They won't be paid members of staff or professionals from a community mental health team or GP practice.

Before you decide whether to take part, it is important to understand why the research is being done and what it would involve for you. Please take the time to read the following information carefully, and discuss with others if you wish.

What is the purpose of the study?

The purpose of the study is to find out the views and experiences of patients and those who care for them. A previous study carried out by the researcher explored the views and experiences of clinical staff, this study aims to build upon the findings of that study and understand patient experience more fully. Patients, carers and clinical staff will then come together to develop the content of a clinical resource aiming to improve care.

Why have I been invited?

As someone who has cared for and supported a person with a history of severe mental illness, and a life-limiting or terminal illness, your views and experiences are central to this research study. The researcher would like to ask you about your experiences, if any, of supporting access to end of life care services, any barriers you have experienced when trying access services, how you feel about the end of life care needs of the person you support and your opinions about how care can be improved.

Do I have to take part?

Participation in this research is entirely voluntary, and it is up to you whether you wish to take part. If you agree to participate, you are free to withdraw at any time without giving a reason.

What will happen if I do take part?

If you agree to take part, the researcher will contact you to arrange a time to meet with you. The meeting will take the form of a semi-structured interview. The researcher will ask you some questions about your experiences and there will be time for you to tell the researcher your experiences and observations about the end of life care available to the person you helped to support, how you feel about the care they received, the barriers you may have experienced in accessing care and your views about how end of life care for people with mental illnesses could be improved.

You will be asked to provide verbal and written consent to participate. The interview length will depend on how much you want to share, but it is expected to be about an hour.

The interview will, with your consent, be recorded. This will allow the interview to be transcribed (written out) afterwards and enable the researcher to analyse the interview for the research study. An external company may be used to transcribe some interview data. Your identity, as well as the contents of the interview, will be kept completely confidential. Any personal information provided will be fully anonymised.

In the interview, in addition to talking with the researcher, you will have the opportunity to write down or draw any thoughts, images or experiences you don't feel comfortable sharing if you prefer. Pens and paper will be made available for this.

Refreshments will be provided if you attend an interview outside your home. Please let the researcher know if you have any specific dietary requirements such as no dairy, gluten-free etc.

At the end of the interview, the researcher will ask you if you would like to take part in the second part of the study and attend the workshops. You do not have to take part in these and participation in the second part of the study is also entirely voluntary.

Travel Expenses

If you take part in an interview, the researcher will offer to interview you at your home.

If you do not feel comfortable with this and prefer to meet at another convenient location, which requires you to travel, the equivalent of bus or standard train fare can be claimed to cover reasonable travel expenses. The researcher will provide you with a form to claim expenses.

What are the possible benefits of taking part?

There are no financial rewards for taking part. However, your views and experiences will shape the findings of this research, which will inform future practice and also inform the design of the next stage of the study. The findings of the research may inform the development of teaching and learning resources, good practice guidelines, policies and procedures for clinical staff and service managers. The findings will also be fed into the development of national policy and practice developments.

The findings will be submitted for publication in a peer-reviewed journal and submitted to Coventry University as part of the researcher's PhD thesis.

What support is available to me if I find participation upsetting?

Talking about death and dying, palliative and end of life care, and mental health issues, may be upsetting for some people. No assumptions will be made about your personal experiences. You will be provided with the contact details of local support services available. There will be time at the end of the interview for de-briefing and discussion with you. The researcher is a qualified Art Psychotherapist, employed by Birmingham and Solihull Mental Health Trust and registered with HCPC. The researcher has experience and understanding of complex mental health issues and the support available to any participant who may become distressed.

Will my taking part in the study be kept confidential?

Yes. The researcher will ensure that the contents of every interview remain confidential and that any personal information provided is kept fully anonymised. Ethical and legal practice will be followed.

At the end of the research study, any identifiable personal data will be disposed of by the researcher. No personal information will be held by the researcher of the University after the research study concludes.

What will happen if I change my mind?

Participation in this study is entirely voluntary and you are free to withdraw from the study at any time without giving a reason.

You may withdraw consent at any point in the process. Data from interviews will be withdrawn from the study. However, if you have participated in a workshop it will not be possible to withdraw your individual contributions to a group discussion.

What if there is a problem?

Will my data be kept confidential?

Yes. All data collected will be fully anonymised and confidential. Recordings of interviews will be destroyed following transcription. Anonymised transcripts will be kept securely and password protected on a University secure drive.

What will happen to the results of the study?

The results will be written up by Jed Jerwood as a thesis to be submitted for the award of PhD in Clinical Research from Coventry University. The thesis will be stored at Coventry University library. The results will also be submitted for publication in a peer-

reviewed journal, will be presented within the researcher's employing organisations and professional networks and at professional conferences.

Who is organising and funding the research?

Jed Jerwood is organising the research, under the supervision of Professor Jane Coad as part of doctoral research programme at the Centre for Technology Enabled Health Research at Coventry University. The research is funded by Coventry University, Birmingham and Solihull Mental Health Trust Research and Innovation Department and Health Education England.

Contact details:

Letter of Introduction

Improving End of Life Care for Adults with Severe Mental Illness: Understanding the views of patients, and their informal care networks, through co-design to improve approaches to clinical practice

Dear Participant,

My name is Jed Jerwood and I am a Health Care Professions Council (HCPC) registered Art Psychotherapist working for Birmingham and Solihull Mental Health Trust and John Taylor Hospice.

I have an interest in end of life care for people with long term mental health conditions. Many patients receiving mental health care have higher rates of life-limiting and terminal health conditions, yet find accessing end of life care difficult, or find end of life care does not meet their needs. Existing research shows that little is understood about the end of life care needs of people with long term mental illnesses, and that there is little information or training available to clinical staff to improve their confidence and skills.

I am undertaking doctoral research at Coventry University to explore how care can be improved. There are two stages to this research study.

Firstly, to better understand the patient's experience of end of life care, care planning, accessing services, and having conversations about the end of care available.

Secondly, to begin to develop an information/education resource to improve the quality and availability of end of life care for this patient group.

I have enclosed copies of the participation information sheet which gives greater detail about the study, how to take part and what will happen to the findings. Thank you for taking time to read this letter and I hope you will consider participating in the research study.

If you would like to take part in the study, or would like to discuss it further, please contact me using the details below.

Yours faithfully,

Appendix 4 – Ethical Approvals

Some materials have been removed from this thesis due to Third Party Copyright. Pages where material has been removed are clearly marked in the electronic version. The unabridged version of the thesis can be viewed at the Lanchester Library, Coventry University

Coventry University

Certificate of Ethical Approval

Applicant:

Jed Jerwood

Project Title:

Improving End of Life Care for Adults with Severe Mental Illness: Understanding the views of patients, their informal care networks, and use of co-design to improve approaches to clinical practice

This is to certify that the above named applicant has completed the Coventry University Ethical Approval process and their project has been confirmed and approved as High Risk

Date of approval:

13 July 2017

Project Reference Number:

P59145

Appendix 5 – Call for Participants: Poster/Flyer and Social Media Wording

Call for Research Participants

Coventry University

John Taylor Hospice

Birmingham and Solihull NHS
Mental Health NHS Foundation Trust

Do you have a long term mental health condition?

Do you also have a life-limiting condition?

Do you help care for someone who does?

Are you a member of clinical staff working in mental health services or end of life care services?

Would you like to participate in a research study which aims to improve end of life care for people with long term mental ill health and life-limiting conditions?

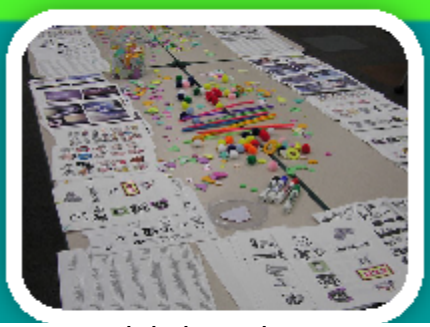
What does it involve?

If you are a patient or a carer there are two stages you can take part in:

- An interview about your experiences with a researcher
- Two workshops with other patients, carers and some clinical staff which aim to develop an educational resource to improve the quality of end of life care

If you are a member of staff you can take part in the second stage:

- Two workshops with other clinical staff from mental health and palliative care services, patients and carers which aim to develop an educational resource to improve the quality of end of life care



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Wording for Social Media

Call for Research Participants

Do you have a long term mental health condition? Do you have a life-limiting condition?

Do you help care for someone who does as a carer or member of staff?

Would you be interested in taking part in a research study which aims to improve end of life care for people who have experienced long term or severe mental illnesses?

Appendix 3 Ethical Approvals

Coventry University Ethical Approval – Main Study

Certificate of Ethical Approval

Applicant:

Jed Jerwood

Project Title:

Improving End of Life Care for Adults with Severe Mental Illness: Understanding the views of patients, their informal care networks, and use of co-design to improve approaches to clinical practice

This is to certify that the above named applicant has completed the Coventry University Ethical Approval process and their project has been confirmed and approved as High Risk

Date of approval:

13 July 2017

Project Reference Number:

P59145

Coventry University Ethical Approval – Literature Review

Certificate of Ethical Approval

Applicant:

Jed Jerwood

Project Title:

Literature Review:

1. How have co-creation methods been used to improve clinical practice in a) mental health services and b) palliative and end of life care services?

This is to certify that the above named applicant has completed the Coventry University Ethical Approval process and their project has been confirmed and approved as Low Risk

Date of approval:

07 February 2017

Project Reference Number:

P47485

NHS REC Approval Letter

HRA Approval Letter

BSMHFT Approval and Letter of Support

JTH Approval and Letter of Support

Coventry University Indemnity and Insurance Certificates

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Amendment Approvals: NHS REC and HRA

2Gether Foundation Trust Letter of Access

Appendix 4 Critical Appraisal

Summary of Critical Appraisal of Studies

Search 1 (End of Life Care and Co-Creation)

Table 25 Summary of critical appraisal of studies (1)

Questions / Papers	Was there a clear statement of the aims of the research?	Is a qualitative methodology appropriate?	Was the research design appropriate to address the aims of the research?	Was the recruitment strategy appropriate to the aims of the research?	Was the data collected in a way that addressed the research issue?	Has the relationship between researcher and participant been adequately considered?	Have ethical issues been taken into consideration?	Was the data analysis sufficiently rigorous?	Is there a clear statement of findings?	How valuable is the research?	Comments Include/Exclude?
1. Blackwell, R. W. et al. (2017) 'Using Experience-Based Co-Design with Older Patients, their Families and Staff to Improve Palliative Care Experiences in the Emergency Department: A Reflective Critique on the Process and Outcomes'.	Yes, clear in abstract and body of text - to use co-design to improve clinical practice	Yes – study aims to understand patient and families' experiences with a view to improving care	Yes, EBCD is evidence-based methodology, staff and patients recruited, findings presented back to wider staff focus groups	Yes, convenience sample of staff and patients, patients recruited during visit to ED Sample size not pre-defined in common with qualitative methodology	Yes, the EBCD method used gives a structure for data collection. Patient and staff experiences collected and shared	Not covered explicitly in the paper.	Ethical approval given by NHS REC, and discussion of ethical issues within the paper is comprehensive.	Yes, thematic framework analysis used, themes agreed by research team, presented back to staff for validation and to check analysis relates to broader experience.	Yes, findings form the focus of the paper. Includes a six month follow up process – interesting in terms of impact.	Valuable – significant given increase in life expectancy and number of older people presenting to ED at EOL.	Include Robust study, using EBCD in new setting, exploring important area of clinical practice, amplifying patient experience Findings focused paper Improving clinical practice
2. Borgstrom, E. and Barclay, S. (2017) 'Experience-Based Design, Co-Design and Experience-Based Co-Design in Palliative and End-of-Life Care'.	Yes - to carry out rapid review of literature and discuss appropriateness of method in PC/EOLC	Yes, although methods not outlined in detail in the paper – which is a summary of a fuller report (not available online – requested from author directly)	Not clear from the paper, states rapid review of literature carried out. However, article does not explain methods or search strategy and refers to a full report which	Unclear how papers were identified for the review - search methods not outlined in paper	Search strategy not included in the article	Not applicable for literature review.	Not covered within the paper.	Not described in the paper – possibly covered within full report, but not available to the reviewer.	Yes, findings form the focus of the article.	Valuable findings, particularly to support the methodological approach of research topic, but disappointing that full report which site behind the paper not available to	Include Useful for methodology chapter Disappointing to not be able to get full report Literature review

			the reviewer was unable to obtain a copy of at the time of the review.							reviewer at time of writing. Useful findings regarding how poorly patients in EOL services are involved in care planning and service development.	Co-design in EOL/PC settings
3. Davies, N. et al. (2016) 'A Co-Design Process Developing Heuristics for Practitioners Providing End of Life Care for People with Dementia'	Yes, abstract clearly states study aim, to develop heuristics to aid staff decision-making using co-design to develop content	Yes, experiences of patients and carers sought, so qualitative methods appropriate	Yes, focus groups and literature review used to inform process Qualitative methods involving patients and carers used	Yes, purposive sampling used to ensure participants have experience of the research topic Patient recruitment n/a due to disease progression; carer and professional focused	Yes, literature review, focus groups and interviews. Literature review informed the topic guide for participants.	Not discussed within the paper.	Ethical approval given by NHS REC. Ethical issues not otherwise discussed in terms of research design.	Yes, limitations of only two iterations acknowledged but process described is robust.	Yes. Each finding or theme outlines and discussed.	Valuable in clinical setting, describes how co-design informs both the outcomes and process of research.	Include Concept of heuristics interesting for methodology chapter Paper describes a move away from policy and procedures as a way of improving clinical practice 'think aloud' process interesting Improving clinical practice
4. Iliffe, S., et al. (2013) 'Modelling the Landscape of Palliative Care for People with Dementia: A European Mixed Methods Study'	Yes, to use co-design and other methods to develop a shared model of care	Yes, mixed methods used (literature review, interviews and co-design groups) appropriate to answer research question	Yes, although patient voice not represented directly, voluntary sector organisations used to represent patient and carer view	Yes, to some extent regarding professionals, but no patients included – not really co-design?	Yes, to some extent however the patient and carer voice was represented by vol sector organisations. Combination of interviews with experts, literature review and synthesis used.	Not discussed within the paper.	Not covered within paper.	Yes, robust analysis and study sits within a much wider study.	Yes, each finding or theme presented and discussed in Discussion section.	Valuable, aims to create a consensus of approach and consistent model of care. Not as well described co-design process as in other studies.	Include Using co-design to gain consensus on developing a model of care Lacks patient and carer voice International aspects Developing model of care

Search 2 (Mental Health and Co-Creation)

Table 26 Summary of critical appraisal of studies (2)

Questions Papers	Was there a clear statement of the aims of the research?	Is a qualitative methodology appropriate?	Was the research design appropriate to address the aims of the research?	Was the recruitment strategy appropriate to the aims of the research?	Was the data collected in a way that addressed the research issue?	Has the relationship between researcher and participant been adequately considered?	Have ethical issues been taken into consideration?	Was the data analysis sufficiently rigorous?	Is there a clear statement of findings?	How valuable is the research?	Comments Include/Exclude?
5. Chambers, M. et al. (2016) 'Service User Involvement in the coproduction of a mental health nursing metric: The Therapeutic Engagement Questionnaire'.	Yes, co-production with users (SU's) of mental health services nursing metric, to assess therapeutic engagement	Yes, study is about including SU perspectives in the design of a clinical tool	Yes, rounds of consultation and co-production activity, refinement of concepts and statements	Unclear – paper doesn't describe how SU's or clinicians were recruited to the study	Yes, workshops, panel, research group, focus groups – SU presence in all	Yes, paper reflects upon the benefits and challenges of SU involvement (SUI) and participation; less focus on how SU's can be equal participants	Yes, NREC approval gained and research and innovation oversight from participating MH Trusts; consent and confidentiality mentioned	Yes, as far as t is described, not the main focus of the paper – could be more developed	Paper describes process of involving SU's rather than focusing on the results of the study – which is appropriate (and useful for the review)	Useful example of an attempt to co-produce a clinical tool	Include UK-based Co-production of a clinical tool
6. Cooper, K. Gillmore, C and Hogg, L. (2016) 'Experience-based co-design in an adult psychological therapies service'	Yes, uses EBCD and assesses its efficacy for service improvement within mental health (MH) psychological therapies service	Yes, service improvement study	Yes, EBCD methodology used	Yes, letters to cohort of current and recently discharged SU's	Yes, Kings Fund EBCD toolkit used and paper focuses on how effective this was	Limited, more focus on relationship between SU and clinical participants	Yes, approvals not mentioned, however, paper covers ethical issues of using EBCD, particularly video, and the implications for SU and clinical participants	Yes, King's Fund toolkit used, and limitations and adaptations discussed within paper	Yes, findings outlined and discussion of key issues	Useful account of using EBCD and its strengths and limitations	Include UK-based EBCD used for service improvement
7. Cranwell, K. Polacsek, M. and McCann, T. (2016) 'Improving mental health service users, with medical co-morbidity	Yes, it is a study using EBCD to improve care pathways between tertiary and primary care for MH SU's	Yes, service users experience sought to improve care	Yes, EBCD offers structured approach, paper covers one stage only	Yes, purposive sampling from previous participants in earlier stages, those with relevant experience recruited	Yes, discussion in focus group of clinicians and SU's	No – article focuses on findings	Yes, outlined in specific section	Yes, rigour outlines, process of coding as a team outlined	Yes, 6 key themes identified, a little unclear in paper structure	Useful account of EBCD approach to improving care pathways and experience of care; account of full study	Include Australia EBCD used for service improvement

transition between tertiary medical hospital and primary care service: A qualitative Study'.										would be useful	
8. Freeman, L. R. et al. (2016) 'Working towards co-production in rehabilitation and recovery services'	Yes, reflective narrative account of the process of implementing co-production	Yes, co-produced, reflective, experiential piece on the process of developing a co-production strategy; article co-produced	Yes, co-produced paper	Yes, took time, specifics not outlined in paper in usual way, but feels appropriate for type of paper	n/a – reflective piece	Yes, this is the basis for the paper	Yes, this is the basis for the paper	n/a reflective piece on process of implementing co-production approach	Yes, presented as challenges and achievements	Very useful to consider the challenges of implementing a co-production approach in a MH setting, although different type of paper – not presented in traditional research study format	Include UK-based Reflective, co-produced paper Service design
9. Gillard, S. et al. (2012) 'Producing different analytical narratives, coproducing integrated analytical narrative: a qualitative study of UK detained mental health patient experience involving service user researchers'.	Yes, looks at differences between SU researchers and University researchers and how an integrated analysis can produce enhanced understanding, new information on an issue	Yes, paper concerns experience of SU's and analysis of qualitative data and co-production of research	Yes, clearly outlined in relation to study aims	Yes, team combined university and SU researchers; patients were recruited from MH in patient units (IPU's) using purposive sampling; range of experiences sought	Yes, qualitative interviews carried out by different combinations of the research team	Unclear, but not the main focus of the paper	Yes, outlined in the methodology	Yes, two stage process described; thematic analysis used and secondary analysis of the interpretation of themes	Yes, themes identified and explained and then discussed and summarised	Useful – considers the impact of co-production on research and data analysis on findings and wider understanding if issues	Include UK-based Co-production of research; co-production of data analysis;
10. Gillard, S. (2012) 'Patient and Public Involvement in the Coproduction of Knowledge:	Yes, similar to first paper by Gillard – concerns co production of research and impact of all	Yes, framework analysis; co-produced data analysis	Yes, paper focuses on team analysis and impact on research findings of different	Yes, recruitment of research team was representative of stakeholders	Yes, paper focuses on knowledge produced as a result of co-produced	Yes, reflective account of impact of SU involvement in research process	No specific section but underpins discussion within the paper	Yes, data from the study and data concerning impact of the co-produced findings	Presented as issues for discussion, appropriate to focus of paper	Useful as above article by same author	Include UK-based Co-production of research;

Reflection on the analysis of qualitative data in a mental health study'.	stakeholders being represented on research team has on findings		backgrounds of researchers on the team		data analysis						co-analysis of data
11. Larkin, M Boden, Z. V. R. & Newton, E. (2015) 'On the brink of genuinely collaborative care: Experience-based co-design in mental health'.	Yes, using EBCD to turn research findings into service improvement	Yes, aims to improve SU experience of hospitalization for early episode of psychosis	Yes, EBCD used to develop findings of qualitative studies into service improvements	Wide recruitment, appropriate for consensus gaining (other methods considered and discussed)	Yes, feedback groups and co-design events (adapted from full EBCD to MH setting)	Yes, in reflections of the process	Yes, NRES approval; consent explored	Yes, EBCD process really explored in findings, rather than just the data itself	Yes, findings outlined clearly	Yes, very useful as focused on co-design methodology	Include UK-based Adapted EBCD (for MH) Service improvement
12. Lwembe, S et al. (2016) 'Co-productions an approach to developing stakeholder partnerships to reduce mental health inequalities: an evaluation of a pilot service'.	Yes, evaluating co-production methods (interviews and focus groups) and engagement of minority group (BAME) in IAPT services	Yes, aims to evaluate participants experience of co-produced services	Yes – co-production used to improve engagement in service	Yes, purposive sampling used to identify appropriate participants	Yes, focus groups and interviews	Yes, partially, the paper and the study itself; participant observes used, seeks to engage users in services they have co-produced	Not explicitly explored, ethics approvals not required as paper describes a service evaluation; however, findings useful to review	Partially, it was triangulated with participants but not wide research team	Yes, findings and themes identified	Useful as it evaluates the impact of co-production approach to service engagement with a marginalised group	Include UK-based Concerns access to MH services by traditionally under-represented group
13. Meddings, S. et al. (2014) 'Co-delivered and co-produced: creating a recovery college in partnership'.	Yes, case study of co-production process in developing a new service	Yes, reflective case study of process	Partially, reflective case study, useful but would benefit from a more structured methodological approach to the results	Yes, wide recruitment of partners and participants/stakeholders	Yes, surveys, open meetings, open approach	Yes, in terms of relationships within the recovery college, not within the research team as such	No, not covered in the paper	Yes, action research and reflective approach	Reflections on themes outlined	Useful in parts, reflection on the co-production process as a process	Include UK-based Co-production of a recovery college
14. Pinfold, V. et al. (2015) 'Co-production in mental health research: reflections	Yes, reflections on co-producing MH research	Yes, reflective viewpoints of research team	Co-produced paper to reflect co-production of research study	n/a builds on Gillard's studies	Reflective account	Yes, in relation to building a co-production research team	Yes, ethical issues explored in relation to inequalities	Reflections by the research team	Yes, within the themes	Useful for epistemology and methodological positions	Include UK-based Co-production within research

from the People Study'.											
15. Springham, N. and Robert, G. (2015) 'experience-based Co-Design reduces formal complaints on an acute mental health ward'.	Yes, adaptations to EBCD for MH setting, impact on service improvements	Yes, aims to improve service, reduce complaints, using EBCD methodology	Yes, EBCD adapted to MH setting and used to improve service and reduce complaints through exploring user and staff experiences and priorities	Purposive sampling to identify participants with relevant experience as well as appropriate support	Yes, King's Fund toolkit used to inform data collection and research process	Partially, reflections of researcher with lived experience included	Yes, partially – some reflections on impact included	Partially discussed, King's Fund toolkit used	Yes, impact of process on ward	Very, evaluates process and outcomes	Include UK-based Narrative approach to change Service improvement
16. Tee, S. and Ozcetin, Y. (2016) 'Promoting positive perceptions and person-centred care toward people with mental health problems using co-design with nursing students'.	Yes, to gain views, analyse themes and use co-design to develop intervention	Yes, interviews, role play, simulation, thematic analysis – to understand stakeholder views and experiences	Yes, partially Interviews; thematic analysis; co-design, role play – could be more robust	Yes, cohort of student nurses	Yes, interviews	Unclear, not described within paper explicitly	Yes, university approval obtained	Yes, thematic analysis; co-design; findings (education package)	Yes, presented as themes, discussion and conclusions	Useful, tackles clinician perceptions via co-design	Include UK and Turkey Co-design with nursing students
17. Terp, M. et al. (2016) 'A room for design: Through participatory design young adults with schizophrenia become strong collaborators'.	Yes, using co-design to develop a phone 'app'	Yes, participatory process with service user participants	Co-design workshops, design techniques, story-boards etc	Yes, participants with lived experience of condition, small group, purposive recruitment of staff	Yes, interview and co-design data	Yes, described throughout paper	Yes, described in detail	Yes, analysis method described in detail	Yes, outlined as themes	Useful as described development of technology/app using co-design with MH SU cohort	Include Denmark Participatory design with young people, technology development

Table 27 Table Summarising Themes Search 1 (Palliative and End of Life Care?

	Article	Summary	Summary of themes
1.	Blackwell, R. W. et al. (2017) 'Using Experience-Based Co-Design with Older Patients, their Families and Staff to Improve Palliative Care Experiences in the Emergency Department: A Reflective Critique on the Process and Outcomes'.	A UK paper exploring the use of EBCD to improve palliative care experiences of older people and their families in ED's. Use of EBCD led to: Higher levels of engagement of patients, families and staff Tangible products and changes to improve care Amplification of the patient experience (vulnerable group) First time EBCD used to engage patients, carers and staff to improve palliative care in the ED Paper is a critique of the EBCD methods and a sharing of the data about the PC needs of OP in the ED setting Some flexibility of approach is needed, and indeed desirable, but use of EBCD is both possible, and beneficial to vulnerable groups Flexibility of EBCD is its greatest strength p.92	Elevation of EBCD as a tool within healthcare – over other forms of co-design Flexibility (of EBCD) Value of flexibility Need for flexibility Improved understanding Informed change Improved relationships Amplification patient/carer voice Amplification of staff voice Power of visual methods Improved impact Stakeholder focused Resource intensive Perceptions of vulnerability Ethical concerns when using visual methods with patients Use of co-design with marginalised group
2.	Borgstrom, E. and Barclay, S. (2017) 'Experience-Based Design, Co-Design and Experience-Based Co-Design in Palliative and End-of-Life Care'.	Literature review of use of EBCD, co-design and experience-based design in PC and EOLC. 12 studies internationally, varying adoptions of CD approaches – inconsistent involvement of patients and carers Summary of full report. Links principles of palliative care to principles of EBCD – person-centred approaches	Elevation of EBCD as a tool within healthcare – over other forms of co-design Similarity of values/shared ethos Inconsistent application of CD approaches (leading to elevation of EBCD) Need for further research Ethical issues of working with vulnerable groups of patients Importance of consideration of ethical principles Value of flexibility Need for flexibility Improved understanding

		Acknowledges increase of use of co-design in healthcare, but limited use so far in EOLC/PC Acknowledges positive impact of co-design approaches but highlights greater need for dissemination, evaluation and publication of studies using these models	Informed change Improved relationships Improved engagement Amplification patient/carer voice Amplification of staff voice Power of visual methods Improved impact Co-designed services more appealing to patients Resource intensive Perceptions of vulnerability Use of co-design with marginalised group Need for more evaluation/challenge in evaluating Methods should be more widely adopted Need for greater dissemination of research
3.	Davies, N. et al. (2016) 'A Co-Design Process Developing Heuristics for Practitioners Providing End of Life Care for People with Dementia'	UK-based, dementia focused study using co-design to develop content of heuristics to improve clinical staff decision-making regarding EOL interventions in dementia patients Paper focuses more on findings of the research than the methodology used	Improved quality of product Enhanced rigour of process Improved understanding Informed change Improved relationships Improved engagement Amplification patient/carer voice Amplification of staff voice Resource intensive Stakeholder focused
4.	Iliffe, S., et al. (2013) 'Modelling the Landscape of Palliative Care for People with Dementia: A European Mixed Methods Study'	An internationally focussed paper using co-design methods to create a consensus for a model of palliative care for people with dementia Alternative approach to methods like Delphi?	Amplification patient/carer voice Amplification of staff voice Improved understanding Informed change Improved impact Improved engagement

		Is it co-design if no patients/carers represented directly? Or is this an appropriate adaptation of a model to achieve the aim of the study?	Consensus gaining Patient-focused/equity of patient

Table Summarising Themes Search 2 (Mental Health)

	Article	Summary	Summary of themes
5.	Chambers, M. et al. (2016) 'Service User Involvement in the coproduction of a mental health nursing metric: The Therapeutic Engagement Questionnaire'.	UK- based study using co-production with service users of mental health services; aims to develop a tool to measure therapeutic engagement between SU's and RMN's SUI ling history within MH, co-production less so and still emerging Study adopts principles of SU as expert, key stakeholder in service development TEQ developed was much more fit for purpose due to involvement and participation of U's and clinical staff, despite not achieving full equity of participation in the co-production process	Co-production moves SU engagement beyond involvement/consultation Amplification of patient/carer voice Service user seen as asset Improved quality of end product Improved impact Stakeholder focused Variable representation Inconsistent leadership of co-design process Sustainability Resource intensive
6.	Cooper, K. Gillmore, C. and Hogg, L. (2016) 'Experience-based co-design in an adult psychological therapies service'	UK-based study using EBCD to improve services in adult psychological therapies investigating challenges which arise when using EBCD in a MH setting EBCD was well received by SU's, staff and stakeholders, modified approach	Flexibility (of EBCD) Service user seen as asset Similarity of values/Shared ethos Co-production moves SU engagement beyond involvement/consultation Elevation of EBCD as a tool within healthcare (over other forms of co-design) Amplification of patient/carer voice Challenge of clinical setting/patient group Need for flexibility Ethical issues when using visual methods with patients Ethical issues when using visual methods with staff Perceived impact on care

			Amplification of staff voice Power of visual methods Improved understanding Involvement in research process as well as design of intervention Fear of speaking out - staff Resource intensive Staff engagement Fear of speaking out - patients Patient/Staff support/training in the method needed Sustainability Need for further research
7.	Cranwell, K. Polacsek, M. and McCann, T. (2016) 'Improving mental health service users, with medical co-morbidity transition between tertiary medical hospital and primary care service: A qualitative Study'.	Australian study using EBCD to improve care pathways between tertiary medical services and primary care for MH SU's Acknowledges the physical ill-health needs of people with mental ill health EBCD as a useful approach, identifies themes from the data, concludes a whole -of-service approach is needed to improve care	Amplification of patient#/carer voice Change of organisational culture Inconsistent leadership of co-design process Inconsistent application of co-design methods Need for more evaluation/challenge of evaluating Use of co-design with marginalised group Patient-focused/equity of patient Amplification of patient/carer voice Improved understanding Power of visual methods Value of flexibility Lack of consistency of analysis of data/generalisability of findings Need for further research Need for more evaluation/challenge in evaluating
8.	Freeman, L. R. et al. (2016) 'Working towards co-production in rehabilitation and recovery services'	UK-based case study, reflective paper, focusing on implementing co-production within rehab and recovery MH services	Achieving equity of participants Amplification of patient/carer voice Amplification of staff voice Resource intensive

		Reflective, co-produced paper located within recovery narrative Using co-production to produce a co-production strategy Moving beyond SUI/participation to embedding co-production principles in the organisational culture	Involvement in research process as well as design of intervention Service user seen as asset Use of co-production with a marginalised group Challenge of the clinical setting/patient group Patient well-being impacts on participation Inconsistent application of co-design methods Need for flexibility Recruitment balance/equity in participation Creating the environment for co-design Change in organisational culture Patient/Staff support/training in the method needed Sustainability
9.	Gillard, S. et al. (2012) 'Producing different analytical narratives, coproducing integrated analytical narrative: a qualitative study of UK detained mental health patient experience involving service user researchers'.	UK-based study exploring how service user involvement in research impacts of research findings. How co-analysis of data produces new knowledge, which can improve services. Little previous research beyond enhanced validity/rigour of analysis Co-production of the research, not co-production methods of collecting data	Similarity of values/shared ethos Value of flexibility Patient seen as asset Involvement in research process as well as design of intervention Improved impact; Amplification of service user voice Resource intensive Capacity building patient researchers Achieving equity of participants
10.	Gillard, S. (2012) 'Patient and Public Involvement in the Coproduction of Knowledge: Reflection on the analysis of qualitative data in a mental health study'.	UK-based study exploring impact of involvement on the research process and findings Knowledge co-production as a tool for evaluating impact of PPI on health research	Value of flexibility Patient seen as asset Improved impact Amplification of service user voice Resource intensive Capacity building patient researchers Achieving equity of participants

11.	Larkin, M Boden, Z. V. R. & Newton, E. (2015) 'On the brink of genuinely collaborative care: Experience-based co-design in mental health'.	UK-based study which explores turning the findings of three qualitative studies into service improvements using EBCD in early hospitalisation in early episode of psychosis Co-design as a tool to turn findings into service improvements – research into practice Adapted form of EBCD used, adapted for MH service, explore implications of using with vulnerable patient group, challenges and successes identified and implications for future practice	Use of co-design with marginalised group Amplification of patient/carer voice Co-production moves SU engagement beyond involvement/consultation Power of visual methods Elevation of EBCD as a tool within healthcare – over other forms of co-design Need for further research Need for more evaluation/evaluation is challenging Inconsistent application of CD approaches Sustainability Inconsistent leadership of co-design process Change of organisational culture Challenge of the clinical setting/patient group Ethical issues when using visual methods with patients Perceptions of vulnerability Value of flexibility Fear of speaking out – patients Fear of speaking out - staff Improved understanding Consensus gaining Achieving equity of participants Creating the environment for co-design Stigma challenged Improved relationships Importance of communication Resource intensive
12.	Lwembe, S et al. (2016) 'Co-productions an approach to developing stakeholder	UK-based study using co-production to engage marginalised group (BAME) in psychological therapies service (IAPT)	Use of co-design with marginalised group Service users seen as asset

	partnerships to reduce mental health inequalities: an evaluation of a pilot service'.	Aims to evaluate participants experience of co-produced services Positive findings, small study, suggests co-production of services helps overcome barriers to access to services	Amplification of patient/carer voice Stigma challenged Improved engagement Co-designed services more appealing to patients Capacity building of patients Improved quality of end product Improved understanding Need for further research
13.	Meddings, S. et al. (2014) 'Co-delivered and co-produced: creating a recovery college in partnership'.	UK-based study – co-producing a recovery college Case study and reflection on the process, using action research Positive impact on co-production on a service-user orientated provision such as recovery college Challenges explored	Similarity of values/shared ethos Patient focused/equity of patient Improved relationships Improved quality of end product Importance of communication Resource intensive Recruitment balance/equity of participation improved understanding Capacity building of patients
14.	Pinfold, V. et al. (2015) 'Co-production in mental health research: reflections from the People Study'.	UK-based study reflecting on the experience of co-producing research; co-produced paper	Achieving equity between participants Involvement in research process as well as design of intervention Patient seen as asset Similarity of values/shared ethos Resource intensive Capacity building of participants Change in research practice Achieving equity between participants Use of co-design with marginalised groups Amplification of patient/carer voice Amplification of staff voice

			Consensus gaining Inconsistent leadership of co-design process
15.	Springham, N. and Robert, G. (2015) 'experience-based Co-Design reduces formal complaints on an acute mental health ward'.	UK-based study using EBCD in mental health setting (adapted) to address the number of formal complaints on an acute in-patient assessment ward EBCD used to address problems relating to staff attitudes and communication, mis-aligned priorities between staff and patients Useful study in relation to choice of methodology and inclusion of narrative and visual methods Co-design used to address observation of problem from clinical setting	Flexibility (of EBCD) Value of flexibility Elevation of EBCD as a tool in healthcare – over other forms of co-design Power of visual methods Improved engagement Amplification of staff voice Amplification of patient voice Patient focus/equity of patient Improved understanding Stigma challenged Consensus gaining Change in organisational culture Importance of communication sustainability resource intensive
16.	Tee, S. and Ozcetin, Y. (2016) 'Promoting positive perceptions and person-centred care toward people with mental health problems using co-design with nursing students'.	UK and Turkey study looking at co-design of education to challenge perceptions of mental illness amongst nursing students Poorly described co-design process Example of using co-design to challenge attitudes rather than service development/improvement Co-design used in relation to a marginalised group Useful paper for background and methodology	Perceptions of vulnerability Challenge stigma Similarity of values/shared ethos Patient focus/equity of patient Amplification of patient voice Amplification of staff voice Co-design process poorly described Data analysis process poorly described Resource intensive

17.	Terp, M. et al. (2016) 'A room for design: Through participatory design young adults with schizophrenia become strong collaborators'.	Danish study using participatory design to develop an app with young adults with schizophrenia, aims to create a more participatory clinical practice in RMN's Co-design process described with vulnerable patient group Co-design is beneficial for working with vulnerable patient groups – impact is felt beyond the impact on the end product of the co-design process; impact on culture of organisations and esteem of patient participants	Use of co-design used with marginalised group Amplification of patient voice Similarity of values/shared ethos Value of flexibility Importance of communication Improved quality of end product Patient focused/equity of patient Improved engagement Creating of environment for co-design Patient well-being impact on Power of visual methods Patient seen as asset Flexibility of co-design Capacity building of participants Sustainability Resource intensive

Appendix 5 Initial list of data items and themes

Initial list of data items and themes

Table 28 Initial List of data items and themes

Theme Number	Data Item	Initial Theme	Emerging theme/Additional Theme/Questions for Workshop 2
1.	- End of life care plan - One-page document about wishes and preferences (rather than legal documents) - Essential information – what are people presenting with? - Planning tool – what is happening? What is planned? Who is involved? - Information stays with the patient - MyCare app/red book (like babies have when they are born - App could be on patient's phone	Patient Held Care Record/Health Information	Information Sharing Better use of technology
2.	- Students learn best through seeing – hospice placements - Hospice placements - Cross boundaries – mental health nurses on hospice placements - General nursing students on mental health placement - Work shadowing	Hospice placements	Experiential learning across placements
3.	- Empowerment from the top down - Organisational culture (MH) - EOLC Champions - Input to staff induction (MH)	Organisational Culture	
4.	- Training each other (MH and PEOLC) - Peer education - Death cafes - EOLC Conferences – who would run? - Forums - Schwarz rounds - Joint MH and Palliative Care day once a year - Networking - Drop-in sessions - Local and national training programmes - Newsletters – who is going write them? - Time and resources limited - Input to core professional training	Training/Staff Development	Ideas for the way in which information could be shared, but acknowledgement of the limitations in knowledge and resource – some acknowledgement that these haven't worked before Time and resource intensive – how many of these ideas could be incorporated into an e-resource

5.	- To improve staff induction, have champions MH and PEOLC - Link workers? - Key workers? - Accompany patients to appointments - Advise other staff about PEOLC issues in MH and MH issues in PEOLC - Contribute to the development of strategy documents	MH and PEOLC Champions	
6.	- Communication - Communication skills - Encouraging knowledge sharing scenarios - Connecting teams/meeting in person - Access to other professionals/teams – so you can ask questions easily - Cross speciality working - Capitalizing on awareness days to share info, make use of trust wide communications	Communication and Partnership Working	Community of practice Interactive resource Q and A online
7.	- Film clips, short written experiences, images - Different formats, engaging in conversation through film, story, presentation, case studies - Short film clips/video 'how will this diagnosis affect my mental health?' - Short videos for training - Bringing together all the current useful content on YouTube etc - Video - Move away from book taught approaches to more creative approaches - Films/role plays - Blogs, videos, day in the life of… - Videos – carers, patients and staff in conversation	Creative/Visual Methods	Patient Narrative Existing resources Centralising information How to……best practice examples
8.	- Patients/service users talking about how it is for them - Information isn't just theory, hearing the patient experience that you otherwise wouldn't is information too - Experiences of staff and patients - Case studies - Interactive workshops, role plays - When people don't know what to do they seek information – when actually it is about changing attitudes not gaining knowledge – building confidence	Visual and Narrative Stories	Changing attitudes Building confidence Competency not just information

9.	- Building confidence through alleviating anxiety and reducing fear in staff (and patients) - Permission to bend the rules - Fear of the unknown - Flexibility - Thinking outside the box - Building relationships - Confidence - Advocacy - Permission to be flexible/person-centred	Culture of Practice/Organisation	What are the rules? Isn't this person-centred care/flexibility? One size doesn't fit all?
10.	- Staff being able to ask questions without judgement - Early conversations and how to have them - Difficult conversations	Difficult Conversations	Communication Skills What are difficult conversations? Is this different for MH and PEOLC and Patients/Carers?
11.	- Flexibility - Inclusive language - Personalised/individualised - Must feel nice to use/handle - Colour important	Qualities of Resource	
12.	- Practical information – - Who is out there? - Who does what? - What about out of hours? - Contact numbers? - Referral points: when, why, how? - Key questions you could ask when you see a consultant (patient-focused) - Timing – when to do what?) staff section)	Information Who is Who? Who Does What?	Emergence of idea of broader audience than staff/clinicians to patients and carers
13.	- Need an overarching message - Person/family at the centre - Person in centre always - Variety of starting points (access points) - Dispelling myths	Myth Busting, Placing the Patient at the Centre	Considerations of audience – what would take the viewer to the resource (variety of starting points comments)
14.	- Website - Intranet/internet-based - Easy to find – accessible - Early ideas of image	Online – Accessible, Web-based	Illustrate with photo examples as you would a quote in an interview-based study?
15.	- Crisis teams (MH) - Education teams (MH and EOLC) - Communicate to CMHT staff and 'older' staff	Audience/End User – Who?	Emerging idea about equity – is it for everyone? Do patients need to build their confidence in the same way as staff?

	- All teams through the life course Available to everyone – nurses, clinicians, patients – it would be powerful to see everyone's perspective - Format appropriate to all		Hosting issues to maximise accessibility – informed question in workshop 2
16.	- Include care pathway/expectations - A resource which crosses boundaries – consider where it is hosted? - EOLC whose role is it anyway? - Everyone's - Can one resource support different professionals, families, friends, carers and patients – capture all perspectives	Audience/End User – Purpose?	
17.	- EOLC should be as individualised as possible - Acknowledge negative past experiences in healthcare of people with MH illnesses - May impact in treatment choices - Dispel myths	Overarching messages 1 principals	Link to TA13
18.	- What does a good death look like? What does a good death mean? - Everyone deals with end of life care - Myth busting – "you won't always have pain" - Stigma challenging regarding cancer and other illnesses - Stigma challenging around EOLC and PC - "Mental health isn't a barrier to receiving good PEOLC" (or shouldn't be) - Culture change – being able to talk about death - "Dying is everywhere"	Overarching messages 2 MH and PEOLC	
19.	- Interactive - Discussion forum - Twitter feed - Q and A's - Opportunity to ask questions	Interactive Resource	Emerging idea of a 'community of practice'
20.	- Professionals should be able to more easily share information and experience - How do we share information when person is too unwell? - Barriers – concerns around confidentiality - Centralised care records system across PEOLC and MH - Central point for info and resources that get lost on web - HCP info – who is involved - Patient info available to all HCP's involved in care - Understanding restrictions around sharing information about a patient	Information Sharing/Access to information	Two separate issues: Resource acts as central point for existing useful information and resources so easily retrievable and accessible Issue of separate NHS records systems and sharing of information between organisations And patient permission/confidentiality- links to ACP and Care Co-ordination in general

	- Policies and procedures all in one place - Systems which talk to each other - Information sharing protocols – good practice examples - Permission to share information - Contact numbers – who do I want contacted (patient)		
21.	- Dementia content - Understanding the dying process in non-cancer e.g. motor neurone disease, COPD, heart failure, Huntingdon's disease, multiple sclerosis, Parkinson's disease	Non-cancer conditions as well as cancer - awareness	Separate resources available for dementia – beyond study remit; however, for patients with SMI who develop dementia there may be some benefit in including dementia specific information/content
22.	- ACP for people with SMI, advice about mental capacity - Education/role play/good practice in undertaking ACP with vulnerable groups of patients	Advance Care Planning	Significant theme – many issues arose in other theme areas which would be addressed by effective ACP; Resource needs to build confidence about how to have ACP conversations in a meaningful way with people with SMI
23.	- Resources for patients and carers - Service directory - What to expect - Care pathway - Film explaining roles, support available, finance, who's who?	Audience – patients and carers?	Links to use of visual methods
24.	- Where to refer people to? - Local and national - Psychiatric/MH services available and how to access - Palliative care services available and how to refer - Statutory and VCS/Charities - Social prescribing	Service Directory	
25.	- Workbook - E-learning courses	E-learning	On what topics?
26.	- Mental health team – info about terminal conditions, guidance about thinking about prognosis, when to refer and to whom - Plan for support through the dying phase for MH team – what support will be needed? - "the only conversations I have had about death and dying while studying as a mental health nurse is suicide prevention and nursing suicidal patients" - Information about the reality and finality of EOL diagnosis for MH staff	Information for MH teams – death, dying, PEOLC	Recommendation for staff inductions (MH) Recommendation for core training (MHN) inclusion of PEOLC

	- Induction input about care through the life course including EOLC (challenge the perception that 'we' don't do EOLC		
27.	- Make use of all the existing resources – they need to be in one place - Links to relevant websites - The worlds of PEOLC and MH are separate so clinicians don't know what's available – bring it all together - Existing resources: - 5-step approach and RAG charts - Treatment models and pathway information - Advanced Communication Skills resources - Age UK resources about EOLC - Video – 'Can You See Me?' - Health Talk - Worcester University dementia film - Vincent Feletti obesity studies - Huntingdon's Disease Association website - Health Unlocked - ALD Manchester resources - MIND - St Mungo's - Regional strategy/policy - Macmillan - Scottish ACP resources - COPD leaflets from association? - NCPC/Hospice UK resources - Royal College of Psychiatrists	Making use of existing resources	Inform question for workshop 2 Existing resource ideas need to be checked and reviewed/verified
28.	- Assessing risk - Managing risk - Sharing risk information - Person-centred care v managing risk/rules - Hospice process re suicidal patients – is there one? - Clinician fear of opening up discussions and causing distress and increasing risk - Different services assess risk differently - Perceptions of risk are variable	Managing Risk – building confidence	Clinician focus on risk – see patient interviews where patients say clinicians focus too much on risk What do people think the risks are?
29.	- Information on a web is publicly available, so why not make it intentionally publicly available? - Need to make sure people know it's there - Information available before you need it – make it a go to resource - Easily retrievable in the clinical setting	Access – format	Web-based resource suggestion Open to patients and carers/general public?

	- Time is a factor – we need timely access - Accessing patient data takes too long for frontline staff in acute settings especially - Right information at the right time		Relates to idea of MyCare type app – recommendation for further research
30.	- Communication skills to support healthcare staff communicate with MH patients - How to connect on a personal basis - Building rapport with person - Conversations - Check with patient and family how much they want to know - How to support open and honest discussions - Empowering patient to talk - 'Tell me what I want to know'	Communication Skills	Much of this is common good practice in MH and PEOLC but not delivered to this patient group – sounds like recommending what is already known to be good practice – resource aims to tackle the 'how' of this
31.	- Information about attachment and loss – how this may be more complex for some people with some mental health conditions – personality disorder for example	Attachment and Loss	
32.	- Human Rights Act - Mental Health Act - Mental Capacity Act - Safeguarding Vulnerable Adults - Deprivation of Liberty - Next of Kin - Equality Act	Legal Issues	Clarity about where these may impact upon where a person can receive EOLC, explanation for PEOLC staff who may not be as familiar as MH staff Requested by staff more than patients like risk information theme
33.	- Tackling challenging behaviour - Managing fluctuating mental well-being and possibly capacity - Management of acute mental health symptoms - Planning for when someone is unwell mentally in advance	Information for PEOLC teams - managing mental ill health	
34.	- Link worker in MH to liaise with re medication interaction with EOLC medication/prescribing - Specific info on mental health medication at end of life and impact on EOLC prescribing - Need for liaison	Medication issues	Some could be covered in this resource but also include in recommendations for practice – partnership working and care co-ordination elements
35.	- Philosophies and practice in MH and PEOLC – views of death and dying in MH very different to in PC – negative outcome - Definitions and explanations of what EOLC is, PC, where and who deliver, how to access etc	Background information on MH and PEOLC – difference in philosophies	

36.	- Allaying anxiety - 'end of life discussions should feel difficult' - "It is difficult, if it doesn't feel difficult you aren't doing it right"	Reducing fear and anxiety – talking about death and dying	Benefit of hearing an PC Consultant say this within the group on MH staff present
37.	- Do we think enough about younger people and end of life care? - Do they have different conditions we should consider such as eating disorders? - Hospice population tends to be older, where do young people (young people under 25) and younger (average life expectancy of a person with SMI is significantly younger) fit into hospice provision?	Information for younger people	
38.	- We need information on assessment – of people with MH and EOLC needs	Assessment skills	

Ideas which fell outside remit of study

Table 29 Ideas which fell outside the remit of the study (for discussion)

IDEAS WHICH FELL OUTSIDE THE REMIT OF THE STUDY			
1.	- Do we think enough about younger people and end of life care? - Do they have different conditions we should consider such as eating disorders? - Hospice population tends to be older, where do young people (young people under 25) and younger (average life expectancy of a person with SMI is significantly younger) fit into hospice provision?	**Information for younger people**	Developing a resource specifically for young people falls outside the remit of the study and the research questions. Accessibility to all people with SMI and the staff who work with them will remain a priority issue.
2.	- Dementia	**Information for people with dementia**	People with a primary diagnosis of dementia who have been previously well were not the focus of the research study. People with SMI who develop dementia are included. Much of the content will be relevant for clinicians working with patients with dementia in PEOLC but this is not the aim of this resource.
3.	- Information stays with the patient - 'MyCare' app/red book (like babies have when they are born - App could be on patient's phone - Centralised care records system across PEOLC and MH	**Patient Held Care Record/Health Information** **Integrated care records**	This was a well-supported idea but falls outside the remit of this study – will form part of clinical recommendations The issue of integrated shared care records is a health system wide issue and falls outside the remit of this study.

Appendix 6 List of suggested existing resources

List of suggested existing resources from all stages of co-design process:

Table 30 Suggested sources of information

Workshop 1 Cohorts 1, 2, and 3	Workshop 2 Cohorts 1,2, and 3	Palliative and End of Life Care	Mental Health	Other/General
	NHS England			•
	IMROC		•	
	SureSearch			•
	Birmingham University	•	•	•
Worcester University dementia film	University of Worcestershire	•		
	University of Lancaster	•		
	Institute of Mental Health		•	
Regional strategy/policy	Local Guidance	•	•	
	Scottish Recovery Network		•	
	The Point of Care Foundation – Schwartz video			
NCPC/Hospice UK resources	NCPC	•		
	Hospice UK	•		
Royal College of Psychiatrists	Professional bodies – RCOT	•	•	
Huntingdon's Disease Association website **ALD Manchester resources** **COPD leaflets from association**	Disease specific websites			•

MS Society **MND organisations** **Parkinson's Disease Association** **British Heart Foundation**				
	Alzheimer's Association – butterfly scheme, Who Am I?	●	●	
	Swan schemes	●		
	Dying matters	●		
Macmillan	Macmillan	●		
St Mungo's	St Mungo's – EOLC vulnerable groups	●		
	Homelessness EOLC – shared learning	●		
	LD and EOLC – shared learning	●		
Scottish ACP resources	Scottish Advance Care Planning resources	●		
	Headspace		●	
	Scottish Recovery Network		●	
	Marie Curie	●		
	Age UK – Having Conversations about dying – books and videos	●		
Health Unlocked	Health Unlocked			●
	HealthWatch			●

	Homeward Bound film – NCPC?	•		
	'I didn't Want That' You Tube video	•		
	Ambitions for Palliative Care	•		
Age UK resources about EOLC	AGE UK	•		•
MIND	MIND		•	
	Journals – Journal of Palliative Care, Palliative and Supportive Care Journal	•		
	Aftercicely50.com	•		
	NICE guidance	•	•	•
Video – 'Can You See Me?'		•		

Appendix 7 Large images from Workshops

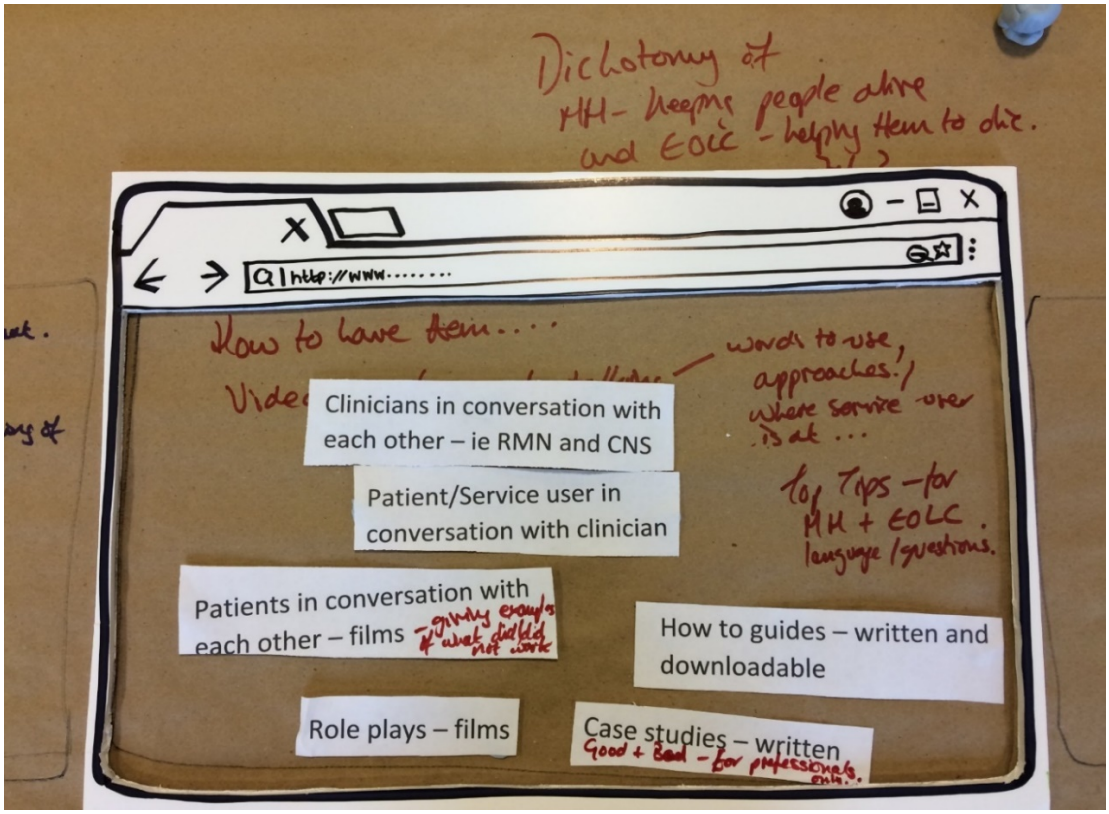

Figure 21 Difficult conversations (1)

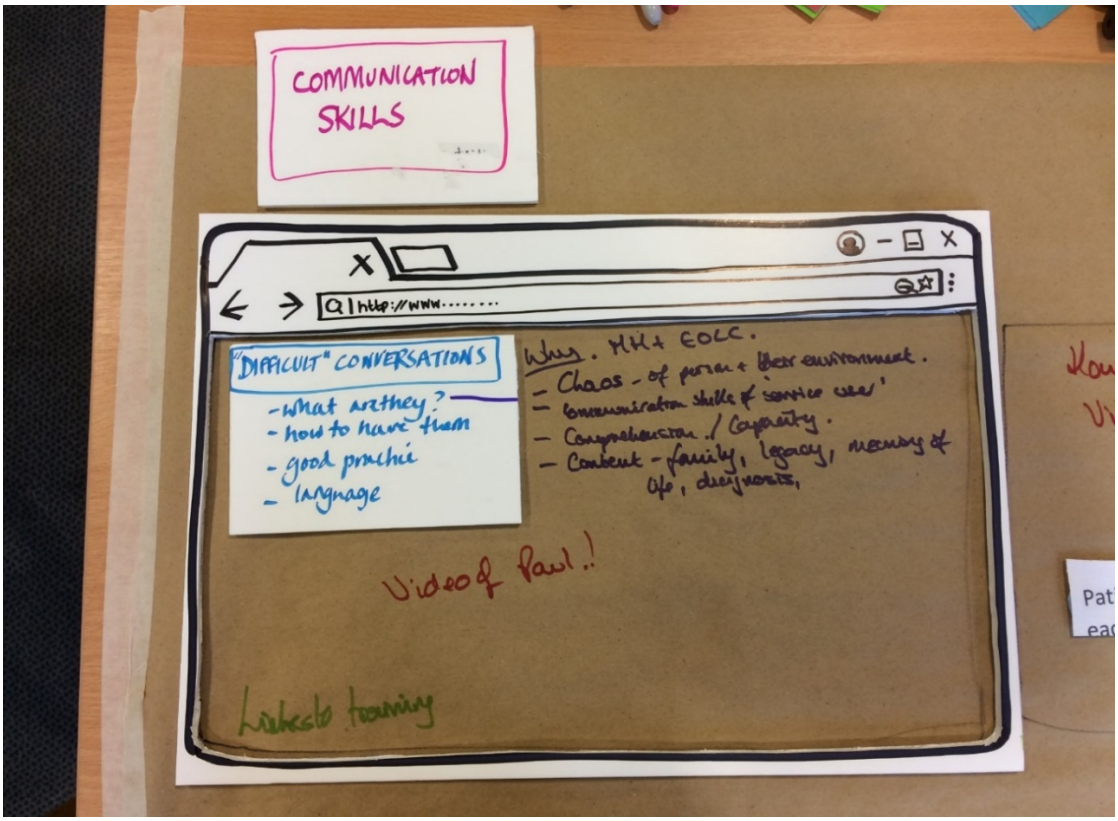

Figure 22 Difficult conversations (2)

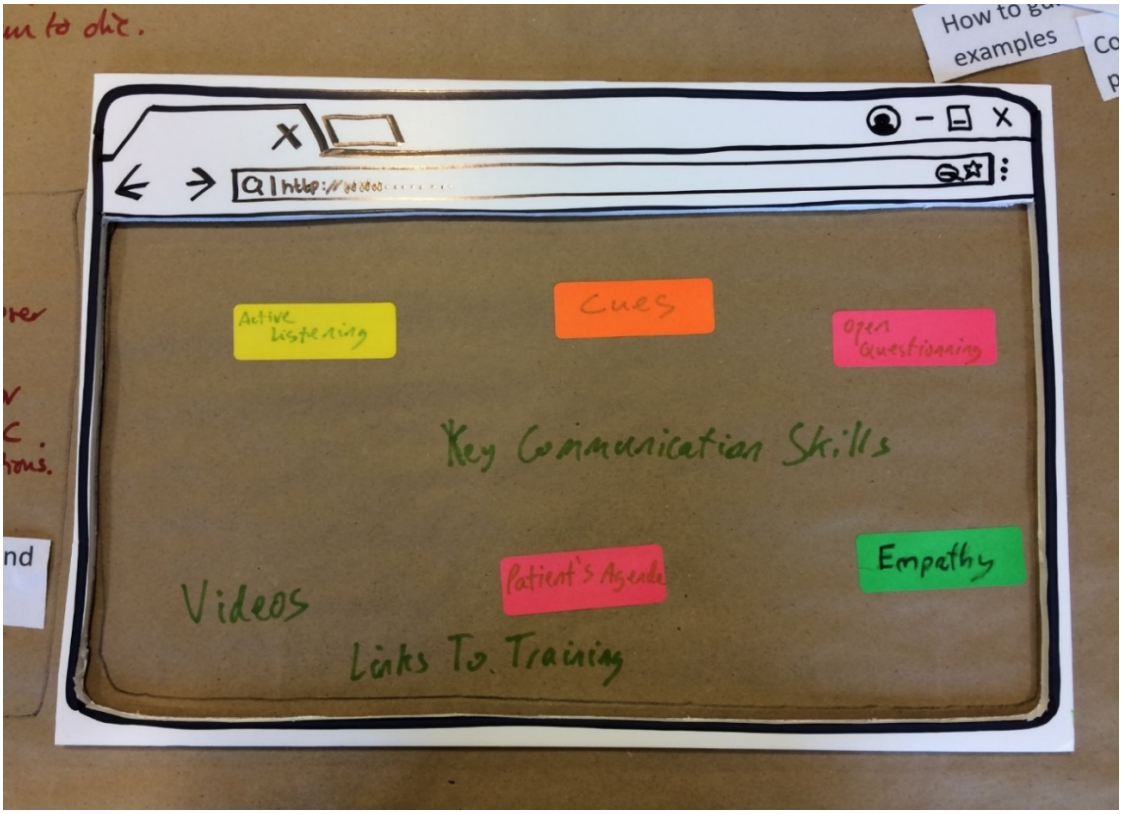

Figure 23 Communications skills

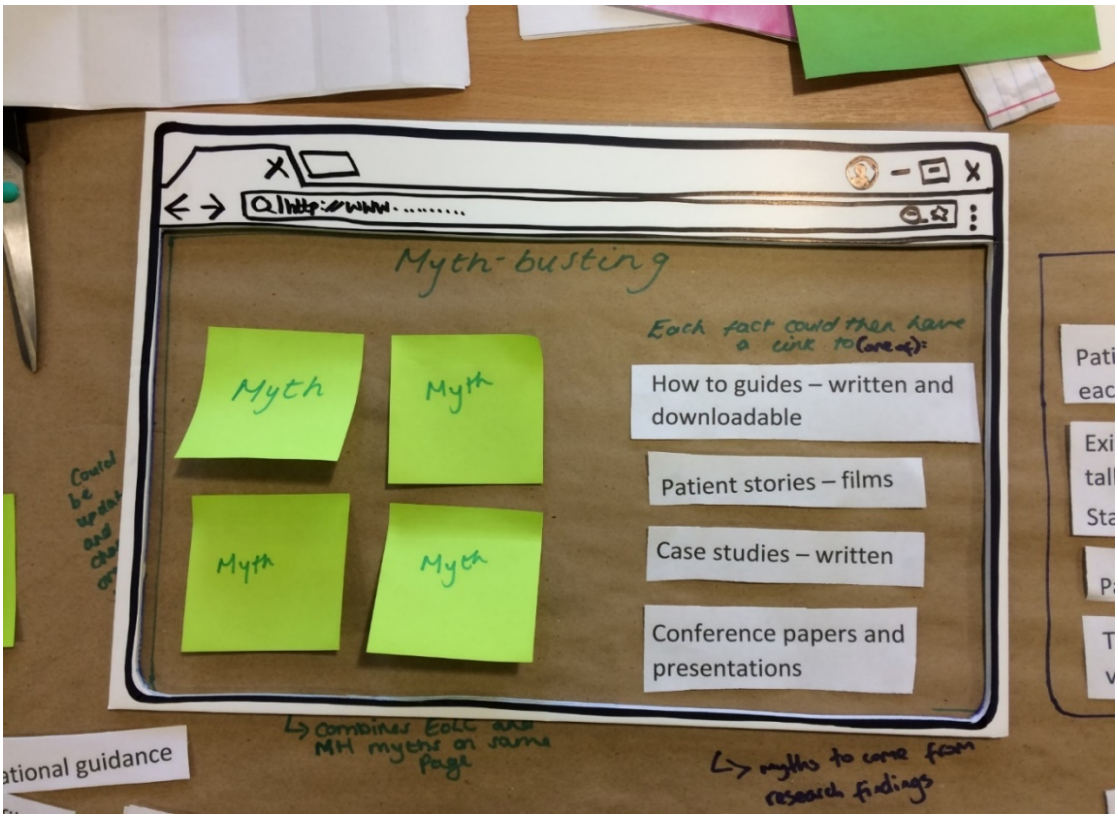

Figure 24 Myth busting

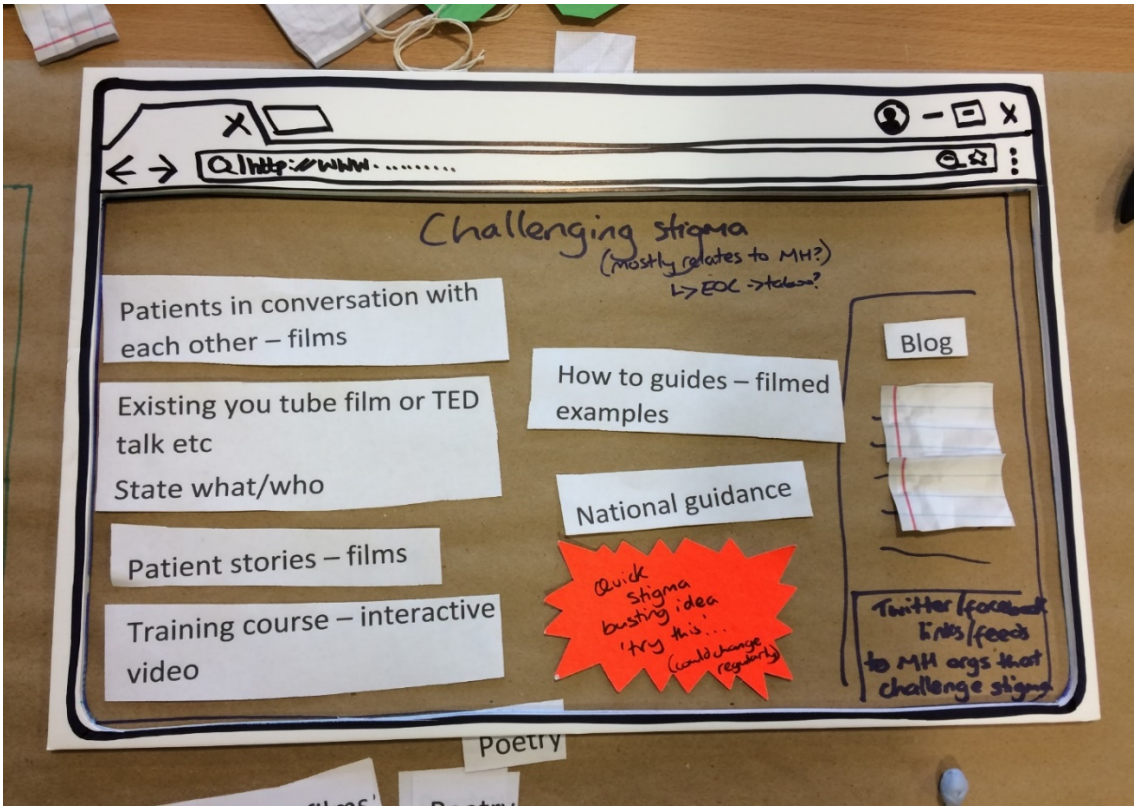

Figure 25 Challenging stigma

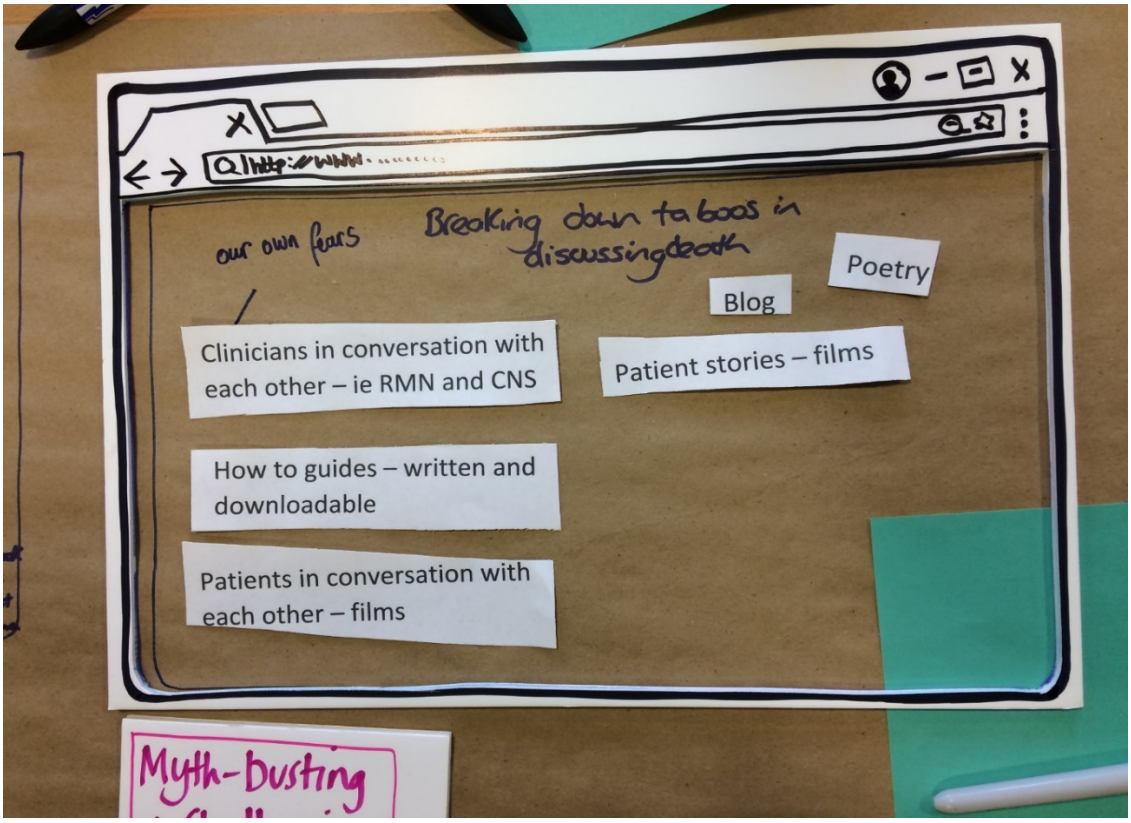

Figure 26 Using stories (1)

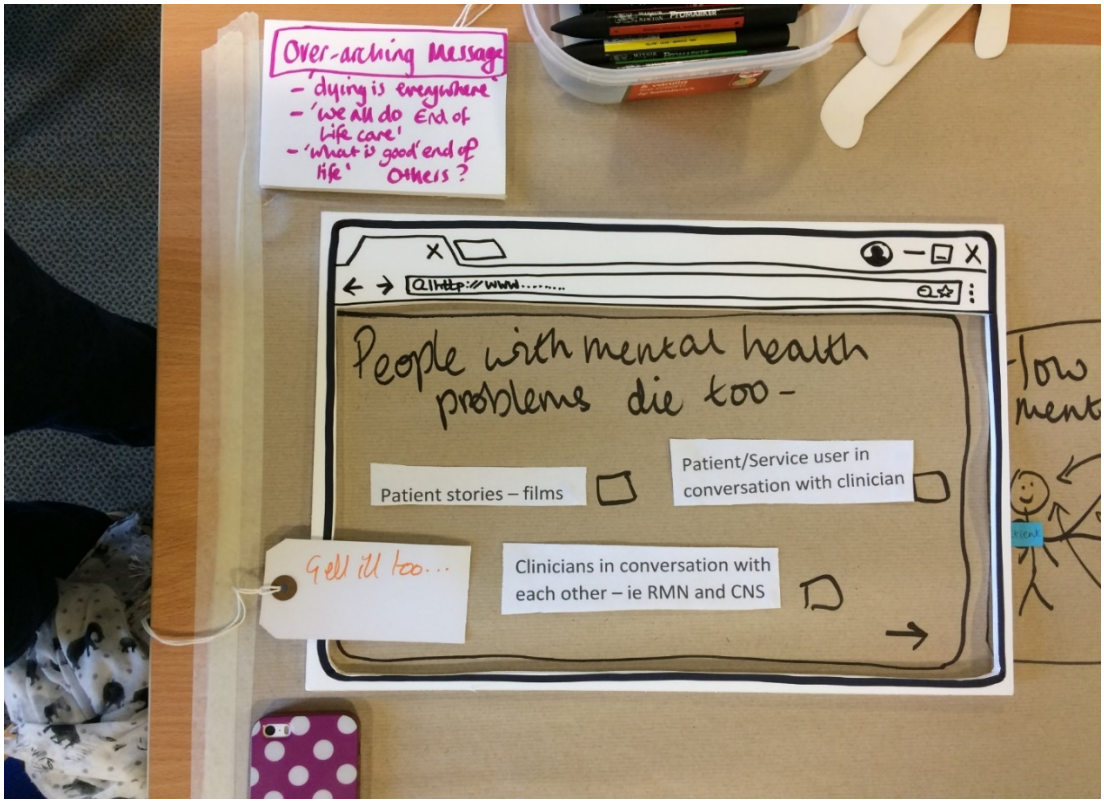

Figure 27 Overarching messages (1)

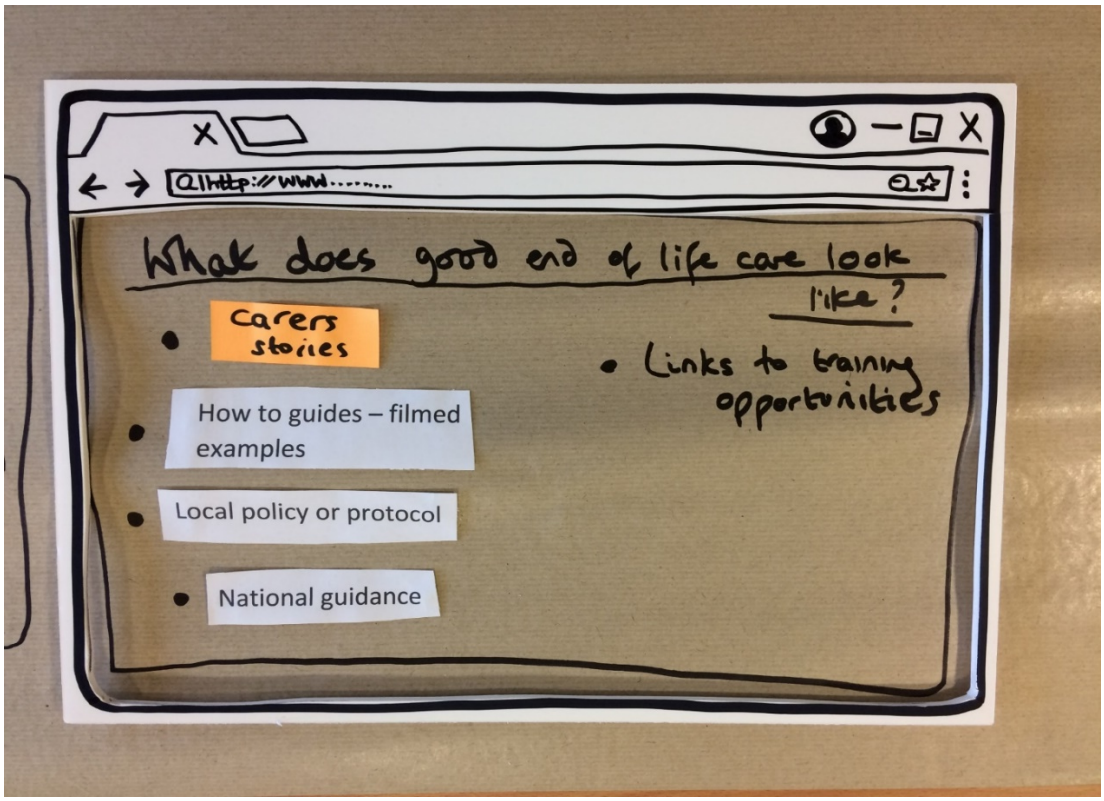

Figure 28 Overarching messages (2)

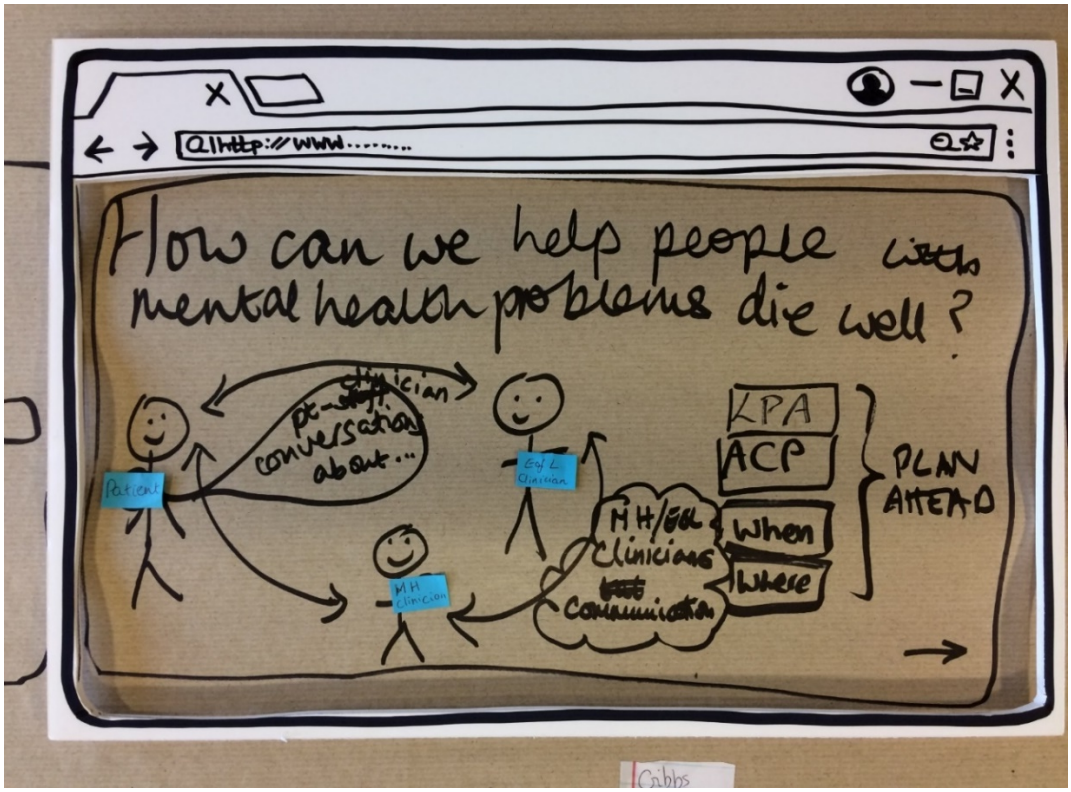

Figure 29 Overarching messages (3)

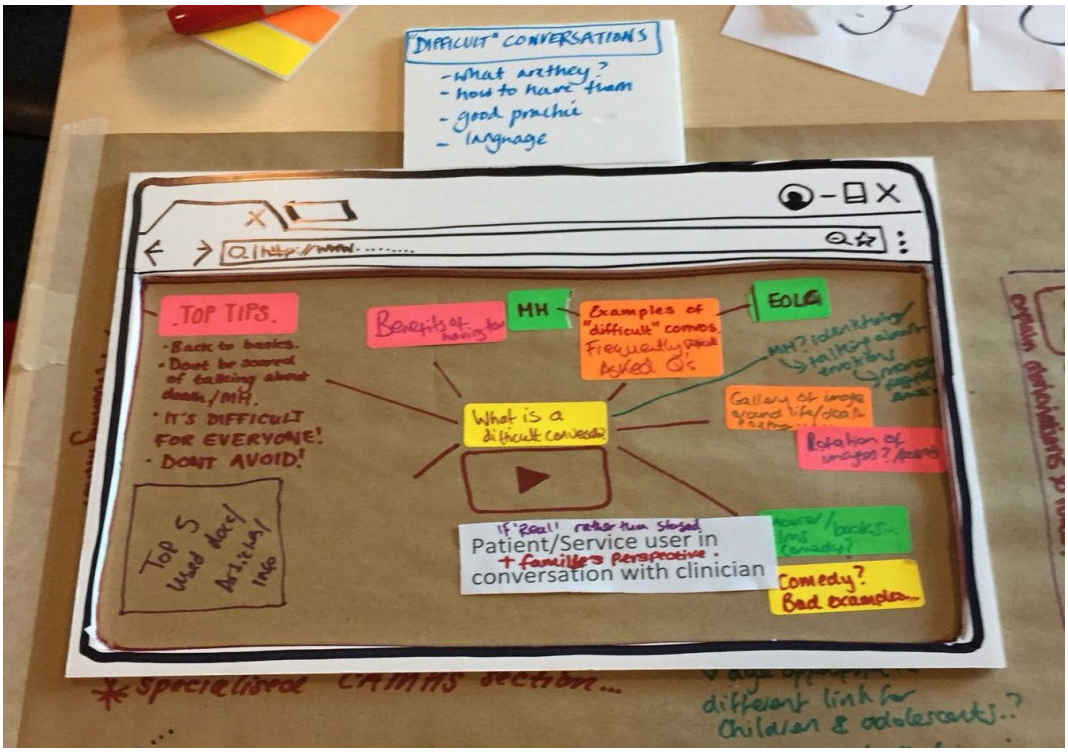

Figure 30 Difficult conversations (3)

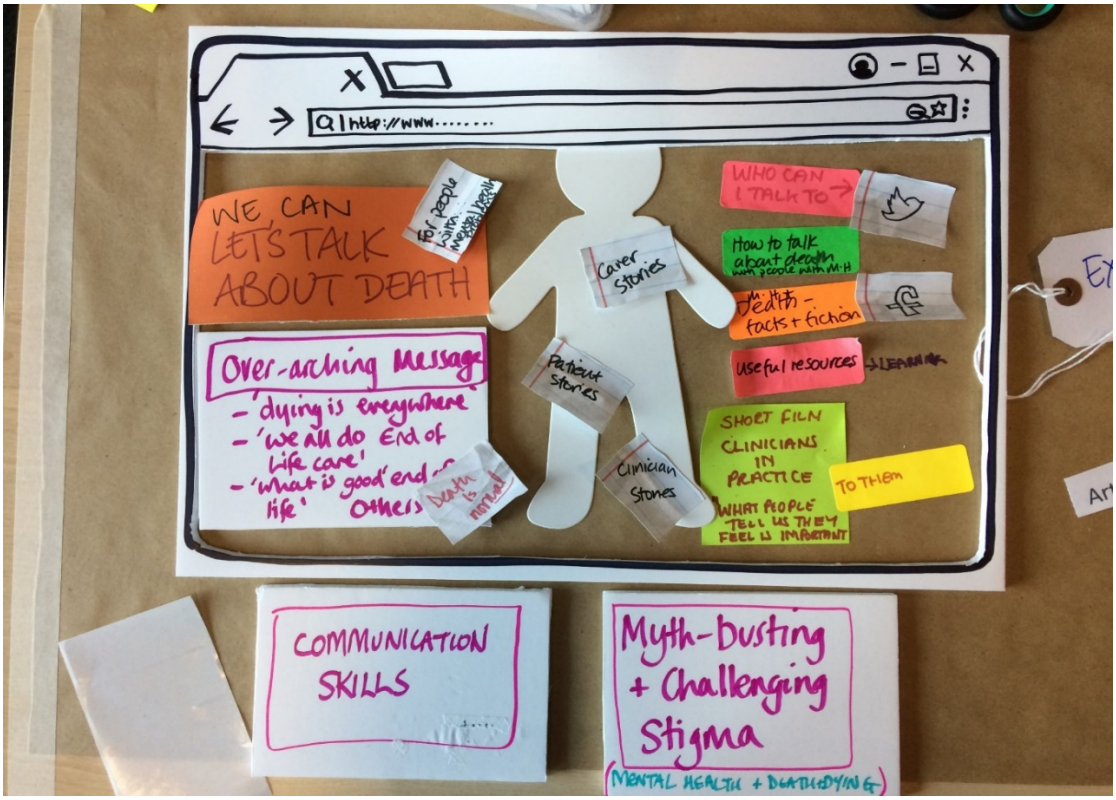

Figure 31 Overarching messages (4)

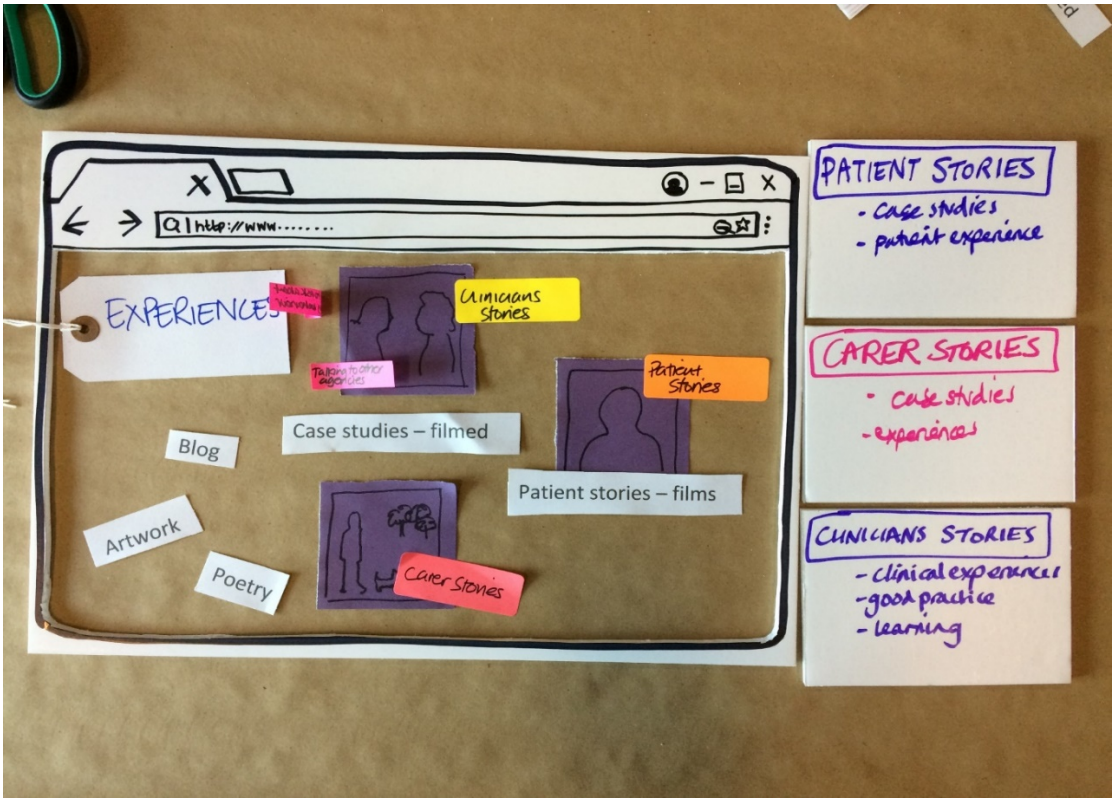

Figure 32 Using stories (2)

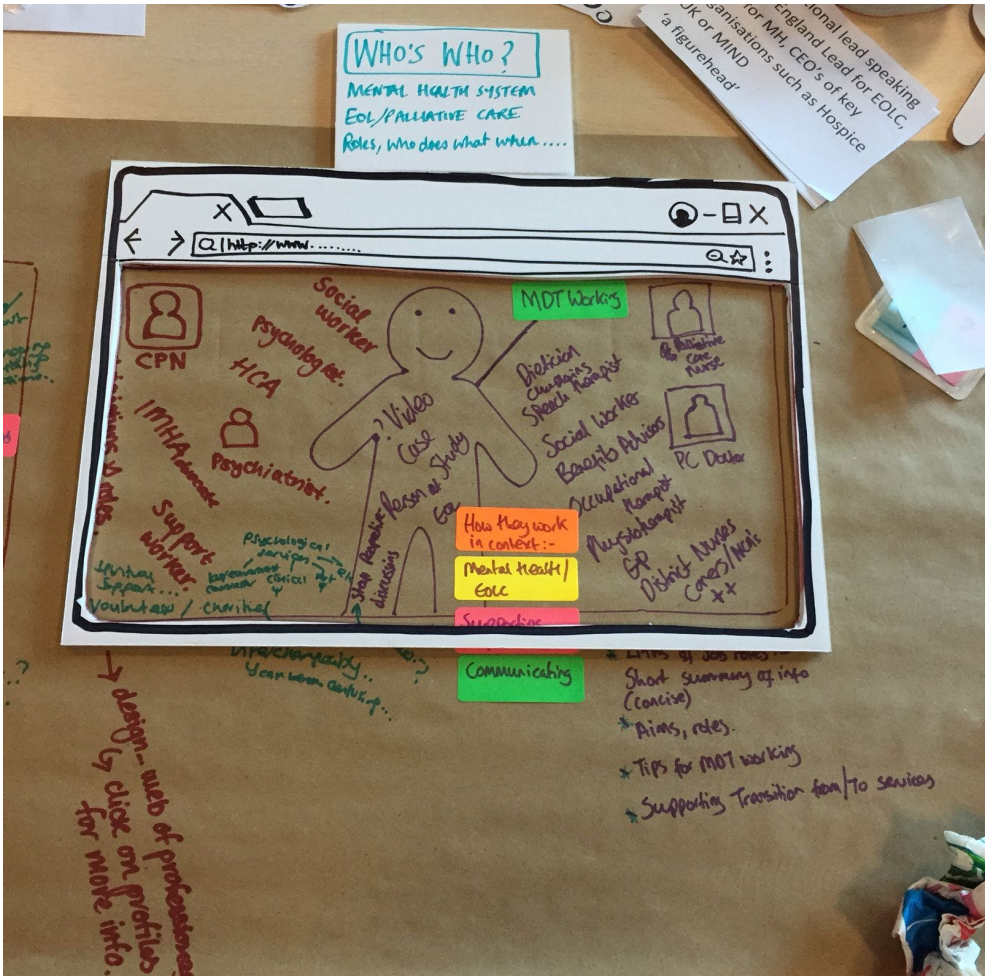

Figure 33 Who's Who?